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Original Article

Empathy - Angel of Humanity against Dehumanization - the Fifth Horseman of the Apocalypse

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Abstract

This study sought to provide a better understanding of the way Jewish population used a series of internal resources to resist, survive and continue thereafter to lead a life as close to what we consider normal as possible.

Trying to identify a theory in order to explain human behavior in situations of terror drove to Terror Management Theory. Despite the diversity of cultures around the world there are some psychological defense mechanisms which have a unique role: defusing awareness of death through a set of beliefs that give meaning and value to life (Solomon, Greenberg & Pyszczynski 1989). The starting point of this theory is the book written by Ernest Backer whose central idea was that awareness of death has a devastating effect, with the risk that the fear of death paralyzes the person (Becker 1976).

To check how the situation of the Jews imprisoned in concentration camps or work camps fits this theory I have used 15 interviews selected from the archives of United States Holocaust Memorial Museum. I have done an initial encoding of 5 interviews obtaining several themes and subthemes. Next, I extended the coding to the rest of the interviews following only the most relevant 6 themes: genocide awareness, leadership, manifestations of empathy, heritage, faith and religious practices, gratitude. Religious beliefs (the promise of immortality, the belief in resurrection, eternal soul and surviving through legacy) seem to support individuals during traumatic experiences and I have examined them in the overall context of religious faith by performing a subsequent qualitative interpretation. Also, I considered following two of the essential virtues from the theory: empathy and gratitude for the preservation of life.

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The results of this qualitative research confirmed only in small measure the theory with regard to Holocaust situation. I assumed two possible explanations for this result: either the terror to which Jews were subjected surpassed the intensity of terror assumed by the theory or the time was a determinant factor (the amount of time during which they were subjected to dehumanizing treatment was too long for most protective mechanisms). Manifestations of empathy probably remain the most important resources.

Keywords: Terror Management Theory; Holocaust; empathy; genocide awareness; coping mechanism.

Introduction. Holocaust – a culmination of dehumanization

The Holocaust was a huge massacre in which there were 6 million victims, including 1.5 million children. The term "holocaust" does not have a Hebrew etymology but a Greek one ("holos" meaning complete and "kaustos" meaning burnt), delineating a ritual slaughter justified theologically. The Hebrew term is "shoa" - total catastrophe (Berenbaum, 2016). Although during the history of humanity many massacres occurred, they, unlike the Holocaust, had a limited extent in a particular geographic area (e.g. the massacre of 1.5 million Armenians by the Ottomans in 1915). The Holocaust was a decision that affected a whole population, wherever its members lived. Identification as a Jew by birth was equivalent to a death sentence. The action of extermination of the Jews was as systematic and complete as possible; there were "only" 6 million victims because the Germans did not have the necessary time to fulfill the entire plan.

Nazi ideology was based on the argument of race superiority and was transformed into a long-term state policy (Richards, 2004). Dehumanization reached the highest rates. Even the terms used are borrowed from the animal kingdom: before 1933 "extermination" was a term for the liquidation of insects. Using this term referring to Jewish promoted the use of dehumanization as a tool for stratifying the races. At the top of the pyramid was situated the German race and at its base, the Jews, a race considered "subhuman", which was a reason to be eliminated (Richards, 2004). Nazi ideology was based on some irrational myths promoting the global perspective about the danger represented by the Jews. The Nazis were planning a new organization of the world according to racial staggering (Friedlander 1995).

Dehumanization of Jews was achieved in several ways: not only by adopting explicit laws but also by imprisonment in concentration, labor, or extermination camps. The concentration camps and the work camps were not an invention of that time, being also used by other political regimes (for example by Stalinist regime in the USSR). However, the extermination camps were Hitler's invention and culminated in the use of modern technology to liquidate the prisoners physically and chemically. To some extent, throughout the war, the Jewish extermination was delayed for "technical" reasons: burying thousands of corpses had raised the danger of epidemics occurring. The technical solution was identified with gassing and burning (Mommsen 2015).

The demonization of the Jew was mainly based on antagonism Christianity - Judaism, Jews being often assimilated to the Devil. This could not have been done without a real propaganda machine. In Germany, Jews represented less than 1% of the population and it would be hard to believe that they could have posed a real threat to the majority.

Propaganda was made through various means (the media, movies, books for children) so that a normal society was put into service of a liquidation machine.

A symbolic representation of dehumanization was proposed by the anthropologist Ashley Montagu. He called the dehumanization "the fifth horseman of the apocalypse" because of the disastrous effects it has on the society. When some people come to be considered as things or animals they become dispensable and any atrocity can become possible (Montagu & Matson, 1983). The starting point is the myth of The Four Horsemen of the Apocalypse who are described in the last book of the New Testament of the Bible; they represent death, famine, war and conquest. This symbolic representation exists both in art and in film. There is a painting made in 1887 by Viktor Vasnetsov (London 2015) and a film produced by Julian Blaustein in 1962 ("The Four Horsemen of the Apocalypse" 2015), both with the same name.

The reason I consider the dehumanization phenomenon worthy researching is, on one hand, the fact that there are historical evidences of recurrences, and, on the other hand, the fact that it has deep roots within the inner human nature itself. The perception that some people are less human can have an anatomical and functional substrate as long as other perceptions and emotions are processed differently by people, as shown by neuroimaging studies through the different activation of some brain areas in the context of the same external information. functionally and anatomically through neuroimaging studies (Phan, Wager, Taylor, & Liberzon 2004). Other analyses revealed the medial prefrontal cortex activation of the subject when exposed to all social groups except extreme (low-low) out-groups, who especially activated insula and amygdala, a pattern consistent with disgust, the emotion predicted by the stereotype content model. The current results empirically support the idea of an anatomical substrate of dehumanization and are consistent with the subjects' verbal reports. By providing neural evidence of the phenomenon, these data go beyond verbal reports, which may be subject to self-presentational concerns. Furthermore, if replicated and extended, this kind of evidence could begin to help to explain the all-too-human ability to commit atrocities such as hate crimes, prisoner abuse, and genocide against people who are dehumanized (Harris & Fiske 2006). Identifying the neurobiological bases responsible for the emergence of dehumanization motivates the existence of such atrocities since early periods of the evolution of the human species. From this perspective, it becomes necessary to understand the phenomenon and to find ways to counteract.

People need to access a series of compensatory mechanisms to deal with terrible anxiety caused by direct observation of death or just thought that death will follow in a very short time. In the literature, different models and processes can be found through which people manage to adapt to thoughts and anxiety related to death; such a process was derived from TMT itself (Pyszczynski, Solomon, & Greenberg 1999). Continuing a somehow normal life, especially after the extremely traumatic experiences of the Holocaust, requires stronger resources. Theoretical aspects of how people react in terms of awareness of death are shown in the following.

Terror management theory - possible explanation of human behavior in the face of death

Terror Management Theory (TMT) was developed in 1986 by American psychologists Jeff Greenberg, Tom Pyszczynski and Sheldon Solomon. They designed it from the writings of Ernest Becker, an American anthropologist, winner of the Pulitzer Prize in 1974 for his

book "The Denial of Death". The defining human trait, according to this theory, it is self-consciousness. Besides its positive aspects, self-consciousness brings to awareness that death is an inevitable event towards which we can exercise no control. Awareness of death has a devastating effect, with the risk that the fear of death paralyzes us (Becker 1976). The same author concludes that man, as a mortal creature, finds himself in the dignified posture of managing to ignore his own fate. He also may feel most free when he leads a secure life, when his life is in his own possession (Becker 1976). In the most general terms, TMT is based on the theory that man is an animal and, like other animals, has a survival instinct. What makes it different is man's ability to think critically about his own being that ultimately brings awareness of own death. We can talk about a conflict between biological survival instincts and conscious fear of death; without some compensatory mechanisms, this might produce paralysis caused by this terror.

Terror management theory explains how people manage to overcome the terrifying fear of death without being paralyzed by anxiety. TMT argues that humans have developed an ingenious unconscious method to manage this anxiety: culture and self-esteem. "Culture" depicts a set of beliefs about reality shared by many people, in order to provide the feeling that the universe has a meaning and an orderliness and that immortality is a possible outcome. Within this paradigm, self-esteem could be defined as a feeling of contempt about one's own person derived from one's values being in accord to the cultural role. Thus, the subject may lead a secure existence and accede immortality. For the purpose of this paper, culture would be defined as a system of beliefs (what is true), of values (what is important) and of expectations (what happens when we engage in certain behaviors) developed by and for a group of people (countries, regions, social groups) to provide the requirements of living (food, water, security, social belonging, respect and meaning) (Bierbrauer 2006).

By developing beliefs shared by a number of individuals forming a group, people succeed to overcome the fear of death; these cultural perspectives give meaning to life through a set of beliefs concerning issues as the origin of the universe, the desirable behavior in life, the promise of immortality in one form or another. Perhaps religious belief systems provide for the most extensive source of worldviews. Those who live up to the religious standards are promised literal immortality, or an afterlife or oneness with the universe, depending on the religious orientation (Bierbrauer 2006).

People have the ability to reflect on their own lives and on their possible dead. In this way, a series of terrible experiences can trigger anxiety related to death. This anxiety related to permanent threat against life is represented by the term "terror" in the Terror Management Theory. Constant reminder of the fact that death can occur at any time and especially in extreme situations causes the "paralysis" described in the theory. Man, can move forward only by activating compensatory mechanisms. In theory, the trigger element is the awareness of death. I followed this idea which I called ***genocide awareness*** in my work with analyzing the interviews.

According with TMT, despite the diversity of cultures around the world, they have a unique role as a psychological defense mechanism: defusing awareness of death through a set of beliefs that give meaning and value to life. All the cultural perspectives on the world are "fictions shared", they continue to exist as a result of social consensus (Solomon, Greenberg, & Pyszczynski 1998). This is essential for the functioning of the defense mechanism, because when everyone around one person has similar beliefs, it is more likely that that person is convinced of the truth of one's own beliefs. A cultural

perspective on the world promises immortality. This acts as a buffer against anxiety caused by the fact that we live in a universe where death is the only certainty. Therefore, when the fear of death comes up, we cling to our cultural perspective with an unprecedented tenacity.

A series of experiments have tried to demonstrate the validity of terror management theory. The first evidence of the validity of this theory came from an experiment conducted in 1989. Researchers have hypothesized that exposure to stimuli that lead to awareness of the moment of the subject's own death ("mortality salience") would lead to the automatic response of strengthening the cultural beliefs used by that person as a defense mechanism against the fear of death. The first study was conducted on 22 Americans judges. They were divided into two groups and asked to complete a personality test. Questionnaires in both groups were identical, except for two questions that only one group was asked. These were intended to remind to the subjects about their own death - for example, they were asked to describe in detail what would happen to their bodies when they die and how they would feel when they think of this. The next task was to study the case of a woman accused of prostitution to determine the amount she should be bailed. The results were that judges who have not thought of death had settled, on average, a 50 $ bail, while those who were aware of their own death decided, on average, a 455 $ bail. The authors' conclusion was that our moral principles protect us from the anxiety of death. The prospect of own mortality increased the need for judges to believe in moral standards. This amplified the desire to punish anyone who violated these values (Rosenblatt, Greenberg, Solomon, Pyszczynski, & Lyon, 1989). This study also included 6 other experiments, of which two demonstrated the role the fear of death has in determining social behaviors.

The same authors conducted subsequent research consisting of three experiments which demonstrated the way the remembrance of death increased attention toward the group of people who shared the same beliefs. It appears that validation of beliefs by consensus that were not observed against the group which does not share the same ideas (Rosenblatt, Greenberg, Solomon, Pyszczynski, & Lyon 1990).

The theory about how the idea of imminent or unavoidable death has been tested in multiple social situations. It appears it acts on the behaviors and practices of individuals by reactivating pre-existing cultural patterns. The interest in TMT is still high. There even has been conducted a meta-analysis which demonstrates that it is a robust theory. It explains how death-related thought in different contexts can generate moderate or large effects on behaviors and cognitions (Burke, Martens, & Faucher 2010). The conclusion of this meta-analysis is translated into a quote by Irvin Yalom, psychiatrist and psychotherapist: "*Though the fact, the physicality, of death destroys us, the idea of death may save us*"(Yalom 2008). Although the literature is full of studies on TMT in social "usual" situations, I have not managed to identify any paper that questions its validity in "exceptional" situations like concentration camps, war theater or genocide.

One of the areas where TMTenables the understanding of human behavior is politics. Ernest Becker argued in his writings that in times of crisis, when the fear of death is more pronounced within the population, people are more willing to accept a leader who gives them psychological comfort by making them feel they participate in a great mission against evil. That is why I tried to discover whether in concentration camps and labor camps leaders were selected, and if so, how they contributed to the survival of the prisoners. ***Leader selection*** was one of the themes encoded in my research.

Many people all adhere to a set of beliefs that motivates us and promises us that, one way or another, life will not end with biological death of the body. Cultural, religious, or philosophical systems permanently existed throughout the history of humanity. These beliefs can take various forms depending on the religion a person adheres to: some people go to church, others to mosque or synagogue. Generally speaking, these beliefs bring hope that soul will continue to exist in another place or that another life will start after the end of the current one. If the religious system is not a choice people may consider an ideal diet or a healthy lifestyle in order to keep death as far as possible. Choosing to have children, to support them and encourage them, can have a similar purpose: children may continue life in form of a genetic inheritance.

British philosopher Stephen Cave studied the numerous ways people imagine that they will live forever. Based on the TMT, he discovered that they all fall into four categories, describing them as "the dream to stay alive", "faith in the resurrection", "idea of the existence of the soul" and "heritage" in his book named *Immortality*, published by Crown Publishing in 2012(Cave 2012).

The dream to stay alive springs from human instincts and occurs in all cultures. Searching for the elixir of youth is a myth that humanity has followed along the centuries. Modern medicine is trying to understand the physiological mechanisms that govern the aging of body in order to slow this process. Belief in immortality is a "promise" the monotheistic religions (Christianity, Islam, and Judaism) employ for maintaining permanent followers. In modern times, especially in case of diseases like cancer, people begin to resort to some promising techniques which are not yet validated. Cryogenics is such a technique. The third belief is the existing of soul as a form of transcending death. Anyhow, scientists failed to confirm the existence of soul, so that in the end, the idea of heritage is the most plausible one for many people. Inheritance may take an individual or group form. We can talk about partially passing our genes to our children, as we can speak about a continuation of existence through inputs we make to our own culture (writings, artwork, various achievements, and fame).

Stephen Cave considers the four narrative structures as the basis of wishful thinking. Although they do not allow us to live forever, they may be used to defeat the paralysis induced by the idea of death, as the terror management theory assumes. To defeat the fear of death, Cave proposes the use of a number of virtues (Barnett, 2012). The empathy reduces our fear of death by orientation to others, by altruistically helping them. Orientation to the immediate present (here and now) may help as enjoy every moment we live, which ensures the resources to continue the fight for survival. The third virtue, called gratitude, depicts our awareness about the fact that life is a chance. All of this prompted me to look in the interviews with survivors of Nazi camps searching for *manifestations of empathy or gratitude, for the existence of an appeal to faith or for heritage as a means of resistance.*

The definition of empathy evolved over time. Carl Rogers was the first to introduce the term in 1957. He defined the empathy or the state of being empathic as a perception of the internal frame of reference of another with accuracy and with the emotional components and meanings which pertain thereto, as if one were the person, but without ever losing the "as if" condition. Thus, it means to sense the hurt or the pleasure of another as he senses it and to perceive the causes thereof as he perceives them, but without ever losing the recognition that it is as if I were hurt or pleased and so forth. If this

"as if" quality is lost, then the state is one of identification (Center for Building a Culture of Empathy 2016). Empathy can be understood in many ways depending on the prevailing side: cognitive or emotional. For the purposes of my work, I have chosen to consider the following perspective on empathy:

- Knowing another person's internal state, including thoughts and feelings
- Coming to feel as another person feels
- Feeling distress at witnessing another person's suffering
- Feeling for another person who is suffering (empathic concern). An oriented emotional response elicited by and congruent with the perceived welfare of someone in need. Includes feeling sympathy, compassion, tenderness and the like (i.e. feeling for the other, and not feeling as the other)

Methodology

Qualitative data provides an overview of the social situations. Further, using our own experience, we may elicit those facts, feelings and actions that represent important starting points. In the case of a serious and extremely complex issue like the Holocaust, there may be difficult to divide the individualized research topics. Even when trying to follow previously well-defined themes, they may not go in parallel lines but may strongly confound each other. People's reaction in the face of death is a constant concern throughout history and even more so in dramatic historical periods in which the number of casualties is high. The ways people have managed to cope with terrifying situations, along with historical memory, may be used as valuable knowledge.

Given my training base as a physician, which I later completed with clinical psychology, my interest was initially oriented to watched medical conditions and treatments offered during incarceration in the camps, as framed it in the rigors and standards of those times. For this purpose, I have made a search in the database of the United States Holocaust Memorial Museum. The query of the database for oral histories retrieved 136 results. Search was done using the keywords: *camp + medical conditions*. Of the interviews, I only selected 20 documents containing many details, in a narrative style, that I saw as "life stories". This approach was useful because I felt that I wanted to see and understand where these people came from, whether they had previous contact with health services, whether they had parents who professed medicine or related professions or could give relevant information in this regard. I have excluded the short interviews with timely responses on places of origin, the camp where they were deported, dates and exact answers to many technical questions. They sounded to me as a testimony before a court, which can be very useful for historical research, but not so much in a qualitative one. In the end, the analysis was performed on 15 interviews.

I started with a codification of the first five interviews; I used a ground coding system (line by line) noting what I considered to be the important themes and their subthemes. I gave these themes symbolical names according to my own perception. For example, I coded the situations referring to death salience (as established in theory) as "awareness of death" or "genocide awareness". At the same time, these issues were viewed chronologically as a global phenomenon of oppression, and they were subjected to analyze according to the progressive increase in intensity.

Some of the initial themes and subthemes, as I coded them, were:

- origins (childhood, positive emotions)

- hiding in community (positive emotions, trust, hide, ethnicity)
- work – first stage (volunteer, medical condition, fright, "joking about himself")
- hiding (trust, community, keeping "the faith", betrayal, communication, differentiation young/old people, family, arrest, hiding "in family", loss of family, false Christianity – hiding religion, war industry for German, hiding ethnicity, new family – positive emotions, confusion, worries about family)
- transport – earlier dehumanization (transport conditions, nationality does not matter, desire to help – repression)
- last stage of dehumanization (first impact with camp, conditions, end of identity, end of human being, "long time for healing", question about "guilt" – surviving, thoughts about survival, work – humility, cruelty in hunger situations, humiliation, medical general rules vs. no standards, cruelty, hopelessness)
- genocide awareness (despair, hopelessness, desire to help, thoughts on survival)
- the way back (losing the notion of time, rename: "death march", physical exhaustion: death, leave behind, battlefield with unarmed people)
- liberation – resuscitation of humanity (logic and opportunity: treatment depending on severity, immediate help, proper treatment in condition of war (primary hygiene), non-discriminatory treatment (including Nazis), transforming a place of horror in a place of healing, reconnecting with people, struggle for life, recoupling with national identity, eustress – positive emotions, propagation of humanity regardless of borders, transfer to home keeping contact for farther support – extension of aid after initial intervention).

I chose to present this list (even if it is not incomplete) to show the complexity of the phenomenon and especially the multitude of information that an interview with a survivor contains. The themes are strongly linked and separation is not only difficult but perhaps unnecessary.

In the beginning, I wanted to address issues regarding the circumstances of medical practice in the concentration and work camps. I later noticed that information is relatively scarce and mainly refers to poor standards or even nonexistent treatments, even according to the rigors of medical practice of the time.

The circumstances in which the Jews lived were of the worst: extremely low temperatures, a minimum of clothes for a long time, food devoid of nutritional value and low in terms of calories. The physical body was subjected to real torture while the psychological life was the subject of a real terror. Death was not just a thought but a continuous presence. Interviews offer an apocalyptic picture, a culmination of dehumanization and un unimaginable suffering. Under these circumstances, the apparent normality these people manifested at the time the interview was taken is surprising. They recount about the way they resumed their lives and about the way they raised their children and they cast messages for future generations. It is almost impossible to identify hate or desire for revenge in anything they say. Legitimate questions arise:

> How did anxiety related to death not cause paralysis? How did these men continue to fight for their lives? Why did the phenomenon of suicide did not become a choice for these people (this phenomenon, although present, was rare – there are stories attesting that they were urged by their guardians to throw themselves to the electric fence)?
>
> Is terror management theory able to explain how they coped such horrors?

Which were the resources that Jews used to be able to overcome the horror to which they were subjected?

Starting from the terror management theory I recoded all the interviews according to the following themes: genocide awareness (death salience), leadership, manifestations of empathy, heritage (legacy), faith and religious practices and gratitude.

Awareness of imminent death triggers a series of emotional and behavioral reactions, designed to reduce anxiety, and allow the continuation of the struggle for survival. I considered this as the starting point in analyzing the validity of the theory. Extremely difficult periods are considered favorable for the emergence of leaders (visionary, authoritarian, or otherwise). This leaders' role is mainly to guide the group towards achieving its objectives or maintaining its values. The rest of the themes I have analyzed may be considered virtues or resources the group uses for more easily tolerating situations in vicinity of death, in order to allow individual or group life to continue, as normal as possible.

My goals were to observe how these themes are represented in the stories of survivors and whether there is evidence that they functioned as important resources during incarceration in the camps. There is solid theoretical evidence that these resources work during "ordinary" social situations, nevertheless, to date, I could not find literature proofs to confirm the validity of the theory during "exceptional" terror situations as the Holocaust.

Findings - Results and Discussion

Genocide awareness – looking death in the face

For the beginning, I tried to find evidence to prove that the Jews were aware of the actions of the Nazi extermination policy. Death awareness is the starting point of terror management theory. It determines several changes in behaviors that may pursue survival as the final aim.

In the interview with Hanni Krispin[1], it is clear that the Jews had knowledge of the Nazi plan since the period before deportation. In this way, they could mobilize resources in the community and try a resistance movement:

> "*She recalls hearing Hitler's speech about the destruction of the Jews on Christmas Day 1941, on a secret radio. The role of the underground was to be there for each other, and to revive the spirit of Zionism. They wrote secret newspapers which had been buried and were found after the war*".

Also, it is shown a symbolic antagonism between Christianity and Judaism: destruction of the Jews was planned to happen on Christmas Day 1941.

Awareness of the dramatic situation was present in all stages. Shortly after the German army withdrawal, when they barely glimpsed the release, the Jews could see a large number of corpses. Waiting for the death became consciously verbalized, as shown in the interview with Arie Kalbenberg[2]:

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[1] Interview with Hanni Krispin, October 3, 1993 – RG-50.029*0034, United States Holocaust Memorial Museum; Retrieved from: http://collections.ushmm.org

[2] Interview with Arie Kalbenberg, January 31, 1991 – RG-50.028*0024, United States Holocaust Memorial Museum; Retrieved from: http://collections.ushmm.org

> *"Many of the remaining prisoners died there. The survivors in the morning had to crawl over feces and corpses. There were no longer any guards. "You waited for death"".*

The situation was similar in all camps, regardless of the authority under which they operated. Even though the circumstances were somehow different, reality of death represented a constant. Sonja Gottlieb Ludsin[3] tells us about hopelessness and continuing fear of death in her camp in Latvia:

> *"There was no way for anybody to be saved. And we knew we were going to die, which, at that time, was actually a relief, because we were starved to death."*

Terror management theory uses the term death or mortality salience. This term represents the awareness of theirs one's own death, in a social context, that trigger various emotional and behavioral changes to reduce the anxiety of the individual. The most common outcome is strengthening their own convictions or beliefs that are part of a solid cultural background. The situation is more dramatic for Holocaust. It is not only about remembering the idea of death (which may recur with a certain frequency along the whole life) but about a direct observation of suppression of life in a large number of people, part of the family, children, or neighbors, without any identifiable rule or fault. I could not find in the interviews stories about how Jews activated or modified certain beliefs such as religious beliefs. My feeling is that they told the story of how they managed to survive each day. The story consists mainly in facts and less in metacognitions of the thoughts, reflections and ideas derived from the internalized situations. The severity of the situation required probably other protective measures.

The leadership role in a convicted society

Hanni's story[1] is relevant with regard to this subject. The resistance movement was led by the formal leaders of Jewish communities and aimed at continuing the Jewish cultural traditions. They were able to manifest only in the early days of the Holocaust, in a clandestine form. It is hard to believe, nor do we have clear evidence, that there was a selection of some leaders in the extremely hostile environment in concentration camps:

> *"Leaders of the Jewish Aeltestenrat (Council of Jewish Elders) would not select the 10,000 Jews as demanded by the Germans; therefore, the Germans took 12,000. After this, the Zionists reorganized in the ghetto. The group was not involved in fighting, but in a battle for the human spirit. The preservation of Hebrew culture and language was their focus, and they taught Hebrew literature to children when possible".*

The resistance movement was a peaceful one; It was politically orientated in attempt to establish good connections with the German authorities. The main purpose was to continue the cultural roots. There are recounted situations where adults read books to children in an organized way. Survival mainly concerned the whole population and was less directed to the individual taken separately (from the interview cited above):

> *"Hanni thinks that ghetto leaders always acted in the best interests of the people. She responds yes when considering the very stressful conditions. She mentions that*

[3] Interview with Sonja Gottlieb Ludsin, July 13, 1994 – RG-50.030*0262, United States Holocaust Memorial Museum; Retrieved from: http://collections.ushmm.org

the leadership, including Dr. Elkes, had helped to establish good relations with the Germans, even with the police. There were several underground groups, including Abezia (?).(...)

The role of the underground was to be there for each other, and to revive the spirit of Zionism. They wrote secret newspapers which had been buried and were found after the war".

Identification of religious leaders and their actions is difficult. There are only short accounts where we can see the power of their voice in the community, although the message is filled with despair. Rabbi's powerful voice is not just a physical characteristic but it represents a the symbolic power of the leader who continues his mission even during the transportation to the camp and subsequent incarceration. Such an image appears in the interview with Joseph Neuman[4]:

"He especially remembered one transport from Paris because it had a Rabbi on it that had a powerful voice." "Skies should have come down."

Hans Herzber[5] recounts aspects of his family life before being deported. Although families were already affected by the arrests of members and the situation in their communities and living up to that time was very difficult, the family institution had not entered a dissolution. A family member, in this case the mother, was forced to take over the role of a binder, to keep them all in a secure environment, as far as possible:

"Q. And so, how was your mother able to cope with this?

A. Mother was very strong. A strength we had never recognized. At this point I became the head of the household."[5]

Discovering the signs of empathy

It is very difficult to differentiate clear manifestations of empathy. We can easily find evidence of support and help among people subjected to an extreme situation. All people formed a kind of death sentenced community, who's each individual fought for a common goal: survival. The manifestation of empathy means putting oneself in the situation of another human, understanding his suffering and emotions, without one being in that situation. All these people were, after all, in the same terrible situation. Abandoning a group member was reducing the chances of achieving the common objectives:

"All night, the prisoners waited in the rain on the ground. They were then taken to a big barn for the night. Next morning they began walking in rows of five, which was very difficult for Hanni's mother who asked to be left, but was helped by the others."[1]

The most important aim was maintaining work capacity, without which the "selection" process that led to the killing would have followed. The work became an object of exchange for survival. Maintaining group cohesion and a degree of hope were obtained by circulation of information about the attempted assassination of Hitler or about the defeat of the German army. The aid to maintain the ability to work took many forms: from

[4] Interview with Joseph Neuman, May 2, 1990 – RG-50.031*0051, United States Holocaust Memorial Museum; Retrieved from: http://collections.ushmm.org

[5] Interview with Hans Herzberg, April 7, 1991 – RG-50.031*0029, United States Holocaust Memorial Museum; Retrieved from: http://collections.ushmm.org

the support of a body with one's own body, as a "crutch", to medical treatment, no matter how poor it was.

> *"Hanni heard from another prisoner about the attempted assassination of Hitler in July, 1944. She talks about how joyous the prisoners were to learn this. Rumors were circulating that it was better to work in trenches, even if very sick, than to wait to be selected, which meant going to the crematorium. Hanni had hurt her knee, it became infected, and she was seen by a Jewish doctor. This doctor also showed her mother how to limp as little as possible."*[1]

The signs of empathy may seem much clearer in the case of people who occupied "favored" positions in the bearing structure. One example is the so-called "runner", who partially detour their responsibilities for helping others Jews who are in more serious situations. Obviously, they exposed themselves to a life threat by helping them co-suffers. Nevertheless, these signs of empathy sprang from a deep understanding of other people and from there humanitarian spirit. Even offering food and helping those in the camp hospital was a heroic gesture, not only because it was an act punishable but also because the lack of food was dramatic to all.

> *"Hanni describes how a "runner" who lived in the revier (concentration camp hospital) would go around the camp, collecting people who needed to go to the hospital. Hanni's mother was met by one of these runners (someone who had gone to school with Hanni) who took her to the revier and had her legs bandaged. This runner found Hanni and brought her to see her mother. Hanni was able to get into this revier and be with her mother because a runner did not have to identify the individuals she moved, only to have the numbers going in and out of the revier match."*[1]
>
> *"Arie became very ill, so that he fainted on the Appellplatz. A J.W. risking his own life in this way, took him to the infirmary, where Arie was unconscious for two nights and three days. When he became conscious the first sight, he saw was that of a man's extremely swollen buttocks, due to a severe beating. He next saw the face of another J.W. who had visited him daily and daily had left him a bit of food."*[2]

The image of a mother who sees her dead newborn baby and the reaction of the other women in the barracks are especially impressive. At one time they seem to be a unified body in front of an agonizing pain:

> *"She had to let the baby die. And we all died with it. I mean, that was so horrible. We listened, the baby was crying, and crying, and crying. And no food was given to her, and she died. And we had to comfort the mother. We were a lot of women in that bunk. But were all like one, all like one."*[3]

Manifestations of empathy from the Germans and especially from the representatives of SS is somehow unexpected within that creepy landscape. However, there are such stories which demonstrate once again that humanity has not completely vanished even in that period. The SS soldier who helps the inmates with little things (the indulgence of some pieces of bread) and then avoids introducing them in the gas chamber represents a great hope for humanity as a whole. The two categories of people, SS and Jews, are obviously in antagonistic positions. Providing help in this situation is remarkable and it may only arise as a manifestation of empathy. Sonja tells us that such "favors" were not done as an exchange for anything.

"Once I got those extra few slices of bread, I was able to give my brother the bread that I got, legally. But how do I get to my brother? I cannot go downstairs. So, this SS man, when he spoke to me, and he gave me the orders, and he told me what to do, and who to tell what they have to do, he spoke to me very nicely. And I said to him, "You know what you did was wonderful. And being as you are so wonderful, can you help me to get my slice of bread to my brother?" And he says, "Yes, I will." (...) And I threw that bread under that machine. And my brother got the bread. And I did it as often I could.(...)

She was not as badly infected as I was, with the body rash, and she was walking step into step, and covering my – the front of my body, so the SS men would not put me in the shower. For whatever, we knew it was for death. We knew it wasn't for anything but death. By her covering me, I think it saved me. So, we went to the left, she went to the left, and the others went to the right, which was to the gas chamber."[3]

Stories like this are scarce and not widely debated. Some of them are even less credible. Such a statement made by Daniel Chanoch[6] has in its center Dr. Mengele:

"He followed Daniel, asking about the 'blond boy'. When Daniel took ill with chicken-pox and was hospitalized briefly, someone came for him with medicine. Daniel thinks that Mengele sent it."

A larger number of manifestations of empathy from the non-Jewish population can be identifies during the period before their deportation (when Jews were hidden to protect them) and at the time of their release. Max Roisman[7]'s story is edifying in this regard:

"Finally, I told them who I am. And she says, "It's unbelievable." She called her husband. He was a real angel, a man. He didn't get, if you hear, if you hear sometimes, gallbladder, he didn't get a gall. [chuckles] Heh! Which it is good, a real nice man. There, they rescued me a few times. They hide us. They did. I have to admit. I wouldn't say that's, that they didn't want something for this, but we didn't get it. (...)

They warmed the water and they washed me. They put me to bed, and they called a doctor. He saw the condition. The doctor recognized me right away, because he knows us before the war. And he says, "You have infected. You need attention." I says, "Doctor, I don't have any money. When I'll get on my feet, I'll reward you." He says, "I don't want anything." And he treated me, and after a few days, I was on my feet."

The receiving of Jews by the German population at the time of their release is deeply emotional. There are clear evidences of empathy and rebirth of humanity. This moment remains deeply marked in memory of Hans Herzberg[5] as evidence that there are people who care about the suffering of their fellow men:

"A. The first thing is that I found out that my mother had sent a small amount of money to the camp so that I could take a train home. I looked like an absolute mess. I went to Berlin and then on to Hanover. By the way, in Berlin we had a very touching experience; the people came to the station and waited with food and money and offers of housing.

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[6] Interview with Daniel Chanoch, April 7, 1991 – RG-50.120*0226, United States Holocaust Memorial Museum; Retrieved from: http://collections.ushmm.org

[7] Interview with Max Roisman, April 22 1985 – RG-50.462*0095, United States Holocaust Memorial Museum; Retrieved from: http://collections.ushmm.org

Q. Who was these people?
A. Germans. Non-Jews waiting for the prisoners. This was quite a contrast from what I had just experienced - it was very touching. It sticks out in my memory that these people did exist, there were people who did care."

Clear signs of empathy occurred within communities before deportation. There are stories about community members who risk their freedom and life to help their fellows. Max Roisman[7] was lucky to receive practical help from a community non-Jew member and more than that, from an SS officer with Jewish origins. The first helped him to feed his family and the second helper made a real plan to escape. Max's story is especially moving, as the one who helps him, the Jewish SS officer, exposed himself to a denouncement that could be virtually be equated with a conviction:

"For about a year. At this time I was, get acquaint--I got acquainted with another man of my profession, a tailor, and he gave me a room. And he says, "You can work with me, and we will share what we will get." He got a lot of work and he couldn't manage, especially when the Germans, the border guards over there, choose him as their tailor. And there weren't too many other ones which they could do the work. We never got paid from them anything, but, if any of them brought a loaf of bread, he shared with me. (...)
S.S. Now, later we founded out that this guy, Schossi, has Jewish inheritance. But one time, when it was really a bad situation, and he knew what it was coming, he warned me in advance to run away. I says, "Look, if I'm gonna run, and this, the town is gonna be circled around with Gestapo and S.S., how am I gonna get out?" He says, "I'll take the post here, and you will run. And when I'll shoot, I'll shoot in the air. Don't worry. Run." And I did. And I survived this time."

The clearest manifestations of empathy come from some people imprisoned in concentration camps who, despite the harsh circumstances they also suffered, lived more intensely the suffering of their fellows subjected to even higher atrocities. The true meaning of a wish to switch places with someone in deep suffering, when oneself is in a position close to death, remains difficult to understand. The story of Joseph Neuman[4] illustrates this:

"Joseph was beaten badly and a nice Kapo, who had been a "German Flyer," took him to the hospital. He had a high temperature. The doctor took a bottle of blood from him. In there, he met a kind Jewish boy named Wessler from Slovakia. When the boy was taken away, Joseph felt "terrible, I wanted to die with him.""

In the same line of thought is manifestation of the generosity by the Jews who, although working in the most macabre place (in the gas chamber), were somehow "favored". Risking their own lives, they were sharing food with other prisoners. After a hard-working day, they could find the strength to walk long distances, late at night, in order to offer food to people in other barracks. Though regarded by the story teller as a singular situation, it is an important to be noticed as a sign of humanity. Lily Blayer[8] says:

"I was helped and she risked her life. There were three lagers, ABC. I was in the A and she came from the C at 4:00 AM or 3:00 AM and brought something for us because her brother was in the gas chamber and so he was a commander and they

[8] Interview with Lily Blayer, August 21, 1988 – RG-50.031*0005, United States Holocaust Memorial Museum; Retrieved from: http://collections.ushmm.org

> *have a chance to get some food so she brought me. It was the only person who helped and some others didn't have any and you couldn't get a contact and the best food."*

Perhaps empathetic manifestations remain some of the most touching testimonies, attesting for the maintenance of humanity in the most adverse conditions. Helping and empathy in various circumstances was essential for physical survival but, more than this, the perception that humans remain humans under harsh times offered hope and maintained early life pure beliefs.

Heritage – a motivation for survival and a legacy to the descendants

It was difficult to identify proofs to demonstrate that the legacy which the Jews leave to the posterity or their children was a resource in their fight for survival. In the spirit of the terror management theory, legacy is an important issue. During the initial period of the pogrom families strived to fight for their children's lives. This behavior is common and general for human species and is certainly met in the animal's world too, in an instinctual way. There are countless stories in which Jews sold their objects just to get something to eat for themselves and their families, run away or hide from oppressions. In addition, separation of the families was a common situation with the lack of information regarding one's family members. The desire to see one's own children in the last moment of life is a common cultural element and is narrated by Zvi Naor[9]:

> *"Suddenly I saw my mother. She didn't see me. I heard her saying: "if I only could see my children for one more time". When Motel came back, I went with him to bring my sister and her friends before she is going to Warsaw. (...)*
>
> *My mother was shot in her back. I heard her last words: "Oyi maiener kinder" (my children). My sister and I continue to run. Then we lied between the dead people and spread some blood on our face, pretending that we were dead too."*

The thought of children and families stopped Hans Herzberg[5] to make an extreme gesture, as opposed to some others who, falling in despair, committed suicide. Although I have not found many such explicit stories, it this possible that they exist and are equally touching:

> *"People were encouraged to run into the fence and electrocute themselves, which some did. I guess the thought of my family kept me from doing these things. I was determined to see my family."* [5]

In all the interviews, survivors' express gratitude for managing to go through and later leading a mostly normal life. The message they cast is very strong and advocates to the collective memory, so that such atrocities do not happen again. The messages urge to normality and appreciation of life; life must go on. Hope and prayer are central in the lives of people who have survived and are now in old age:

> *"It's very important that people should know what happened and that it shouldn't happen again because we allowed evidence and experience in our life. It's very*

[9] Interview with Zvi Naor, N.A. – RG-50.120*111, United States Holocaust Memorial Museum; Retrieved from: http://collections.ushmm.org

scary. Very many...and it's very hard to see it going on again and fight again...Let's hope and pray.(...)

I wish I could tell you some better things. We survived and we lead a normal life...we call it normal. I have a very good husband who takes all the trouble with me and I have a son who is nice and we have grandchildren and we try to enjoy what we have. That's all we can do. Life is for living. A normal condition...you have to go on living." [8]

Some of the survivors have developed a set of rules or a motivational phrase to accompany their children during their lifetime. Their torment would become useless if their message remains unheard. Thoughts about what they would leave behind are much more present nowadays in the survivors' minds than during the Holocaust. It might be the fact that now they managed to process the information, while during that times, imminent death did not allow insights:

"- I can't see how people throw away food. I have to finish everything from my plate.

- I taught my kids to be strong, to protect themselves.

- The word "I can't" is not in my vocabulary and so I educated my children.

- I'll never be late" [9]

"people should eat today, save a little for tomorrow if you can, but don't make plans for the next generation." [4]

The messages contain fear that such atrocities may repeat and urges active and constant actions against politics that could lead to genocide again:

"All I can say is that genocide is possible at any time. "Do not be quiet... It will not blow over." [4]

"To me, this is the biggest, the best thing that could have happened." [3]

"Our revenge is to be strong in order to ensure that things such as the Holocaust will never happened again. I taught my children not to be afraid. When I made a bath to my son, I wash him with hot water and then with cold water, so he will be strong and brave."[9]

The legacy of the Holocaust survivors is a thinking which goes far beyond the framework of their own generation or their ethnic group. They call to the memory of recent history, a time when abominable deeds happened, even not to the same extent. Hence, their appeal is firm and strong, as without this heritage their life would have no meaning. Their messages reach to the humanity as a whole; their legacy is the same for every person on the planet. A profound appeal to history is made by Philip Solomon[10]:

"(...) Never Again!" I, inside my own mind, it translates to, "Ever Again!" Because with what I predicted in that letter, almost from the day that World War II ended, there has been genocide from, on every continent on this earth. In Africa, from the northern, from Libya on the shores of the Mediterranean, all, Uganda—where they...killed millions of their own people, the entire continent of Africa, the Middle East. Right at this moment in 1987 the genocide that's going on in, say in

[10] Interview with Philip Solomon, May 28, 1987 – RG-50.120*111, United States Holocaust Memorial Museum; Retrieved from: http://collections.ushmm.org

Afghanistan. And I think probably the worst of all, on a per capita basis, probably much, much worse than the Holocaust in Nazi Germany, the genocide in the Southeast Asia—Cambodia, Vietnam, Laos, where again, they consume their own people, by the millions. South America, the Argentine, and Chile. And my total thinking there is that this is going on and going on, something that I thought would have to end. And my feeling is that as long, relating all this to the phrase, "Never Again!" my feeling is that as long as genocide is permitted to exist on, in, against any people, anywhere on this earth, it can happen again to any other people anywhere else on this earth. (...)"

Faith and religious practices - Factors of stability

Religious ideas are part of the deep culture and represented a central element of resistance. Although they have been forced to renounce their faith, Jews continued to believe in their true God, despite the enormous fear they felt. The importance of faith was even greater if we think that in an extremely hostile environment, one where every piece of bread was gained through fight, these people risked their lives in hiding Bibles and spreading the faith among prisoners. Arie Kelbenberg[2] says that he could not have survived without his faith:

"Asked about his reaction and thoughts at this time, Arie responds that his reaction consisted of a mixture of pride on his belief, and following the true God, and of enormous fear. In Sachsenhausen the J.W.s were originally kept together, but later on they were spread around the camp. This allowed arie to "spread" the word. He did talk Bible with other prisoners, although possession of the bible was forbidden. Some J.W. got together in the morning and gave each a daily text for study. (...)

In Vught and in Sachsenhausen he, and all J.W.s were asked to renounce his faith. They refused. (...) Arie states that he is convinced that without Jehovah he could not have survived."

In some cases, faith is the last resource to reframe the whole existence and hierarchy of values. Being together with family members is regarded as the greatest treasure. Material possessions were practically of no importance. Biblical themes such as punishment are looked at as possible reasons for the horrors that were happening. This explanation, no matter how irrational or inconclusive, provided for the opportunity to continue the fight.

"We only said, please God, let us only be left together. We did not care what we left behind. Material things don't mean anything anymore, If you fight for life, and the ghetto life was not – it horrible, but it wasn't – because we didn't believe it was going to get any worse. We felt, oh, this is going to be our punishment. And after that, the War will be over, and we will be saved." [3]

Jews relationship with faith may be circular. In the worst circumstances faith, may be compared to a skeleton that supports the entire body and becomes stronger once the danger has passed. It is a message, a legacy which does not refer to people, their children, or ethnic groups but rather to the very essence of their inner beings, their cultural heritage. A message devoid of hatred, no longer looking for any guilt, refers to the atrocity as to something that ultimately strengthened the Jewish faith.

"I don't know of any one of the Jewish religions who said, "Hey, we better give this up, we might be next." I think if anything, my own feeling, my own faith is stronger than ever, because haven't we gone through this all through history and

survived? This, certainly, there was no, never anything comparable to this, but I think, you know, to answer the question, no, my faith is stronger than ever because of this." [10]

Religious ideas neither do constantly appear through the interviews, nor are extensive in their amount. For this reason, they may not be considered an essential resource in overcoming the crisis in the face of death. I would say they occurred sporadically or were even absent. There are moments when religious ideas are even put into question or divine existence falls into doubt. We might expect that certain individual resources helped people to cope better with the anxiety of death. Nonetheless, it seems that neither the level of education, nor the social status or beliefs durability were essential factors.

"When asked why he survived, Neumann responded by saying that "more educated...more smart people died...People ask me why and I have to ask myself why. We must believe in something." (...) "Some believe that there is "no God", others say it kept me alive." (...) When asked if Elie Wiesel statement that Auschwitz was of another planet, Neumann responded by saying "he described it well." "It was survival at all costs." Competition to survive. Joseph said that when new transports came, they were all equal. But time distinguished and separated who could make it or die." [4]

The existence of God falling into doubt, luck, chance, or hazard replaced it. The human system of beliefs and values cannot tolerate the existence of a God who abandons his servants. Thereof, the psyche must find a breakthrough to keep its balance:

"It was luck. Just luck. A matter of luck. There was no way to get out. I feel that if I had to wait for the US to liberate, I didn't have any strength left. I was fading away. (...) We didn't get help from anywhere. (...) And there was a God. We looked up many times and thought it was the same sky that we saw at home." [8]

Challenging the faith and replacing it by chance in the cognitive process the person leads a legacy to future generations. In the end, there appears a possibility that so many peoples' death could be tolerated (although not accepted). In this context, it is likely that religious ideas have been less a resource compared to the legacy for the descendants:

"-Did you lose faith in Auschwitz?

-Yes, definitely. I tried to keep it. Mainly, when I came back and saw what happened because you don't visualize. You see it but you don't visualize it when you come back to the emptiness. And I said, "What is this all about?" I was first fasting on Yom Kippur in Auschwitz, but I haven't fasted since I came back. I don't feel guilty. I talked to others a long time ago, we don't talk about it now and we do the same thing.

-Survivors?

-We fasted enough. We did our share and we don't want to fast. That's all. It's not that we're convinced that they don't have to do this. It's just bitterness. It will stay with us until the end.

-What would you say to future generations?

-Try to do everything so that it shouldn't happen again. That's why I am here. I will come because I can't take this..." [8]

At the time of release from the extermination camp, there appear the dawn of normalization. The former inmates resumed the course of their religious beliefs and practices. Liberators and liberated participated in a common ritual in front of collective graves. Death was present all around, both as a thought and as an overwhelming entity, in the presence of so many bodies. It may be that the religious systems are functional in many conditions but, during huge atrocities, they become ineffective or are abandoned. From the interview with Dr. Charles Frog[11] we find:

> "Dr. Froug and the other Jewish members of the unit, about 18 doctors, accompanied them to say the Kaddish prayer for the dead, who could not yet be buried because of the Sabbath. Sunday morning, 8,000 people were marched from the city to dig a large, single grave, 200 by 50 by 10 feet."

No matter how affected faith is in horrible situations, it is part of human heritage and is passed on. Faith might not have been an important resource during the Holocaust, nonetheless it has a particular importance when resuming to a normal life.

> *"And I'll go out, and one time, when he did come in, on a Friday night, when the candles was lighted with my wife and by my boss' wife, and we feel uncomfortable. I am not a fanatic Orthodox, especially when I was younger, I was more liberated in Judaism than I am now. But when he says something, and he says, "I swear by the holy candles," our suspicious that come through with this. This is Jewish roots somewhere." [7]*

Gratitude - useful virtue in dealing with death

According of the principles of the TMT, gratitude for being alive despite heavy ordeals may play an important role in reducing anxiety towards death. It was difficult to identify experiences that prove such an interpretation. It is true that there are stories on the aid received from community members, Hebrew and non-Hebrew, or saving interventions during concentration. Strong emotional outbursts by the survivors took place when meeting rescuers after the end of the Holocaust. Rescuers association with divinity was not incidental under the circumstances. Considering all these aspects, it is difficult to appreciate that the theoretical grounds were fulfilled with the particular situation of terror within the Nazi camps. I chose two illustrative examples in this regard:

> *"He saved me. He was alive until recently. I saw him, and I thanked him, again, and again, and again. (...) I spoke to him over the phone, and I thanked him. And I told him I will never forget him, as long as I live. And I didn't, because he saved my life. (...) He saved me. He told the other SS man not to kill me. And it was like God sent somebody to take this person, to live, which was another miracle. And we were in the death camp." [3]*
>
> *"Yeah, she grabbed me by my shoulders, and she was yelling, "I've found my liberator!" She was just totally hysterical. She was screaming, "I've found my liberator!" I, she was crying and screaming, "I've found my liberator!" And she was hugging me and shaking my shoulders. By that time, there must have been like 500 people in this hall, and her husband quick jumped up, grabbed her, led her back to her seat." [10]*

[11] Interview with Dr. Charles Froug, N.A. – RG-50.035.01*0001, United States Holocaust Memorial Museum; Retrieved from: http://collections.ushmm.org

Conclusion and further directions of research

TMT is a solid theory for the mechanisms a person employs in facing death during usual social situations. It explains the way certain behaviors modify when people face the idea of death.

The main theoretical resources that a person engages for diminishing death anxiety are empathy, gratitude, leadership, legacy, and religious faith. The trigger for activating these resources is death awareness.

I conducted qualitative research using the components of this theory as themes for encoding 15 interviews with Holocaust survivors. The findings of this research show that the coping mechanism used during extreme terror do not entirely fit the TMT model.

I could not find in the interviews stories about how Jews activated or modified certain beliefs such as religious beliefs. They told the story of how they managed to survive each day. The story consists mainly in facts and less in metacognitions of the thoughts, reflections and ideas derived from the internalized situations. The severity of the situation required probably other protective measures.

The resistance movement was led by the formal leaders of Jewish communities and aimed at continuing the Jewish cultural traditions. They were manifest only in the early days of the Holocaust, in a clandestine form. It is hard to believe, nor do we have clear evidence, that there was a selection of some leaders in the extremely hostile environment in concentration camps. Identification of religious leaders and their actions is difficult. There are only short accounts where we can see the power of their voice in the community.

It is very difficult to differentiate clear manifestations of empathy. We can easily find evidence of support and help among people subjected to an extreme situation. Clear instances of empathy are those implying actions of "favored" inmates, who helped their co-sufferers with the risk on their own life. Empathetic manifestations remain some of the most touching testimonies, attesting for the maintenance of humanity in the most adverse conditions. Helping and empathy in various circumstances was essential for physical survival but, more than this, the perception that humans remain humans under harsh times offered hope and maintained early life pure beliefs. The mechanism of empathic action fit's best with the theory thus justifying the chosen title: "*Empathy - angel of humanity against Dehumanization - the fifth horseman of the Apocalypse*"

The legacy of the Holocaust survivors is a thinking which goes far beyond the framework of their own generation or their ethnic group. They call to the memory of recent history, a time when abominable deeds happened, even not to the same extent. Hence, their appeal is firm and strong, as without this heritage their life would have no meaning. Their messages reach to the humanity as a whole; their legacy is the same for every person on the planet.

Religious ideas neither do constantly appear through the interviews, nor are extensive in their amount. For this reason, they may not be considered an essential resource in overcoming the crisis in the face of death. I would say they occurred sporadically or were even absent. There are moments when religious ideas are even put into question or divine existence falls into doubt. We might expect that certain individual resources helped people to cope better with the anxiety of death. Nonetheless, it seems that neither the level of education, nor the social status or beliefs durability were essential factors.

According of the principles of the TMT, gratitude for being alive despite heavy ordeals may play an important role in reducing anxiety towards death. It was difficult to identify experiences that prove such an interpretation. It is true that there are stories on the aid received from community members, Hebrew and non-Hebrew, or saving interventions during concentration. Strong emotional outbursts by the survivors took place when meeting rescuers after the end of the Holocaust. Rescuers association with divinity was not incidental under the circumstances. Considering all these aspects, it is difficult to appreciate that the theoretical grounds were fulfilled with the particular situation of terror within the Nazi camps.

The results of this qualitative research confirmed only in small measure the theory with regard to Holocaust situation. I assumed two possible explanations for this result: either the terror to which Jews were subjected surpassed the intensity of terror assumed by the theory or the time was a determinant factor (the amount of time during which they were subjected to dehumanizing treatment was too long for most protective mechanisms). Manifestations of empathy probably remain the most important resources.

A general overview of survivors' cognitions shows that positively centering the thoughts upon external issues (others – empathy, leadership, and gratitude, future – heritage and religious beliefs) may be a protection factor against death during extreme terror. This is also confirmed by Beck's(Beck & Haaga, 1995) theory of depression and leads to the conclusion that fight for survival may be lost due to depressive traits. Further research using Beck's theory for encoding the interviews (positive/negative vison on self, the others and the future) may lead to a better explanation of the leading psychological mechanisms that predict the survival under terror.

Studies that show how people cope with the atrocities of war and their exposure in the face of death are justified in the current geopolitical instability situation and resurgence of terrorism.

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Original Article

The Influence of Institutional Contexts on Entrepreneurship

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Abstract
This article empirically examines various hypotheses about young people's perceptions of entrepreneurship. Bulgarian, Italian, Turkish, Romanian, and Maltese students participated anonymously and voluntarily in a survey conducted simultaneously across five universities in these countries. The results were analyzed comparatively.
Traditional perceptions suggest that young people in the Global South lack entrepreneurial drive, but the findings offer new perspectives. Although students are intensely interested in entrepreneurship, few are inclined to start their own businesses, with most expecting to work in salaried roles. This seeming contradiction stems from limited access to information, opportunities, and training. While many students aspire to excellence and creativity, they are also aware of lacking practical resources, balancing a desire to learn about entrepreneurship with an understanding of the need to adapt to available opportunities.

Keywords: Entrepreneurship; youth; sociology; education; democracy.

Background

This research originated as an extension and in-depth exploration of a European Union project, "Academic Entrepreneurship Roadmap", funded by the Erasmus+ Programme, Action type KA220-HED - Cooperation Partnerships in Higher Education, 2023. The University of Plovdiv Paisii Hilendarski is the coordinator of the project. The partners

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include “Gheorghe Asachi" Technical University of Iasi in Romania; The University of Malta in Malta; the Çanakkale Onsekiz Mart University in Türkiye, and L'Aquila University in Italy. A project partner is the *Association for Support of the Development of the Intellectual Capital*, a non-governmental Bulgarian organization.

The primary objective of the project (Angelova and Pastarmadzhieva 2024a) is to explore pathways to success in entrepreneurial endeavors, aiming to inspire students' initiatives in a tailored manner. This involved bringing together students from diverse social backgrounds, with a particular focus on those who feel discouraged in their studies and need to catch up to their peers. The project aims to provide training materials, foster an entrepreneurial culture, and give students the necessary skills to start their own businesses under the guidance of academic entrepreneurs.

We present a study based on data collected through the responses of students who participated anonymously and voluntarily in a survey administered simultaneously to Italian, Romanian, Turkish, Bulgarian, and Maltese students.

During the research, we arrived at an unforeseen interpretative idea. In summary, while students are strongly willing to pursue entrepreneurship, their actual propensity to start a business remains low. This apparent contradiction is due to the lack of information and training that students receive. Most of them have great aspirations towards excellence and creativity, but at the same time, many are sadly aware of not possessing the practical and institutional means. They would like to learn more about the entrepreneurial world but recognize that they need more opportunities to learn and develop their skills. This is the prevailing and characteristic trend in the survey responses and in the subsequent analysis we did to interpret research data we did not expect to find.

Our first survey yielded results that were surprising in many respects. The exploratory aspect of our search has become increasingly relevant. Exploratory data analysis (EDA) is an open-ended approach focusing on understanding data characteristics without applying a distinctive model. Typically used in the initial stages, EDA helps identify patterns or deviations before deciding on structural or stochastic models. Tukey argued that statistical research overemphasized hypothesis testing (confirmatory data analysis) while more exploration was needed to generate new hypotheses. Mixing EDA and confirmatory analysis on the same data can lead to bias in testing only hypotheses suggested by the data. Hence, the EDA philosophy advocates examining data independently before applying probability models. In exploratory analysis, data are reviewed with an “open mind” before applying a specific interpretative model (Tukey 1977).

During the research, we highlighted the topic of the drive for entrepreneurship. Drive theory suggests that organisms have interior needs. A drive is an instinctual need that can determine an individual's behavior. Scholars improved this perspective by studying social facilitation, which shows that people perform better in the presence of others. Experiments supported this idea, finding that individuals were more likely to act on their dominant or most practiced behaviors when observed by a selected public. One experiment demonstrated that people's choices were influenced by an audience, enhancing some actions more than others (Zajonc 2006).

Later, on drive motivations, neuroscience directed the relevance of the context to extreme consequences. For instance, it has been hypothesized that mood is linked to the brain's temperature. Over time, various disciplines have conducted essential studies and research to define better and delimit the origins of motivations. In summary, the relevance of the context was the most in-depth point, with a thematic field of influence that goes from

brain temperature to local economic and political-cultural situations. The social facilitation theory is coherent with standard cultural sociology (Côté 2021), so we adopted this perspective, which was perfect for interpreting our data.

The survey data were supplemented and re-evaluated through in-depth interviews, focus groups, discussions with teachers, families, observers, and experts, literature review, and analysis of other research on the same topics. Further comparisons were conducted with university students' responses from other parts of Italy, in regions characterized by strong entrepreneurial spirit, such as Lombardy.

Additionally, the research conducted in L'Aquila demonstrates local integration into a global context. L'Aquila's young people are in sync with their peers in the global civil society, which is growing worldwide and expressing values of creativity, innovation, and peace (Gammone 2017).

Our project aimed to be genuinely *glocal*, connecting reflections on youth entrepreneurship in the local context of L'Aquila with insights from other regions worldwide that demonstrate a robust entrepreneurial culture. We planned a series of meetings aimed at comparing our local situation with other national and international realities, first of all, the United States and China. We searched for a comparison between the microcosm and the macrocosm, hoping to find valuable lessons.

We have highlighted the possibility of peaceful coexistence by promoting entrepreneurship in ideas and culture. Today, understanding the potential for entrepreneurial collaboration between countries and cities such as L'Aquila (macrocosm and microcosm) could provide cultural stimulation and civil growth. Exchange relationships are inherently beneficial for all; peaceful exchange relationships promote the well-being of individuals and understanding between people.

Our specific point of view on entrepreneurship

It is relevant to emphasize a particular aspect in which we frame our study. Entrepreneurship has been examined through various disciplines, with its definitions evolving over time. At its core, entrepreneurship is a process by which individuals or groups create value, profit, business, and innovation by identifying and exploiting opportunities. So, entrepreneurship is a creative act that frequently benefits society in many ways, even if definitions vary depending on the emphasis—risk-taking, resource allocation, or economic impact. We have retraced the previous definitions, emphasizing the relevance of the institutional context within which the entrepreneurial activity takes place.

For millennia, the word entrepreneurship did not exist. The term was coined, joining preexisting nouns, and is a loan from the French. It first appeared in a French dictionary in 1723.

Previously, the word "adventurer" was used in Britain with the same meaning. The word did not exist because the thing did not exist, or at least it designated something that had recently been born and, therefore, was not yet defined precisely and consciously. This makes us understand how entrepreneurship is a concept typical of the Western world (Weber 1923; Schluchter 2009) and consequently absent as a practice in those realities that need to be economically developed adequately. There can be no entrepreneurship if there are not some primary conditions, among which freedom has been emphasized for a long

time, even if it is only one necessary factor among many. Just as the free market was essential for Western history, the rule of law was vital (Bingham 2011).

The earliest definitions of entrepreneurship stem from economic theory in the early 19th century, primarily through the works of Jean-Baptiste Say, who defined an entrepreneur as someone who brings together resources and labor to produce merchandise, emphasizing the role of productivity in the market. Say identified the entrepreneur as a driver for economic growth and provided a broad characterization, saying that it "shifts economic resources out of an area of lower and into an area of higher productivity and greater yield."

Schumpeter, the father of entrepreneurship theory, emphasized innovation, defining an entrepreneur as an individual who "creatively destructs" by introducing new products, processes, or ideas that disrupt existing markets. (Schumpeter 1934). Later, behavioral approaches to entrepreneurship focused on the entrepreneur's actions rather than specific attributes. For example, Peter Drucker emphasized that entrepreneurship is not confined to business but includes any innovation act, such as creating a new organizational process. The old definition underscored that the process of change proceeds across institutional fields (Drucker 1985). This is our main interpretative point.

In a bibliography that has become increasingly broader and more multifaceted over time, our perspective has given greater relevance to the context and opportunity-based definitions (Kirzner 1973), which saw entrepreneurship as the act of identifying and exploiting opportunities in a market, defining entrepreneurs as alert individuals who notice profitable discrepancies in supply and demand. This approach has broadened by emphasizing the pursuit of opportunity without regard to resources currently controlled (Stevenson 1990).

Resource-based definitions highlight how entrepreneurs acquire and deploy resources strategically to gain a competitive advantage. These definitions focus on how entrepreneurs gather resources—including social capital, financial assets, and knowledge—and allocate them in contexts that maximize returns on investment. (Penrose 1959; Barney 1991).

Psychological perspectives define entrepreneurship based on traits, motivations, and social backgrounds. Psychologists (McClelland 1961) identified a high need for achievement as a critical driver for entrepreneurial action, suggesting that entrepreneurs are motivated by intrinsic goals. Sociologists have explored how societal factors, such as family background, education, and networks, shape entrepreneurial behavior (Granovetter 1973).

The need to highlight the relevance of the context to explain the birth and development of entrepreneurship is particularly evident in our case, as the research is dedicated to an analysis of entrepreneurship within a specific context: Academic Entrepreneurship. This specific kind of entrepreneurship refers to the activities within universities and research institutions that promote the commercialization of innovations developed by their academic scholars. It goes beyond traditional studying and teaching roles, encompassing efforts by scholars to translate academic knowledge into viable economic applications. This elaboration includes spinoff companies, patenting and licensing technologies, collaborative partnerships with industry, and fostering entrepreneurial mindsets within academic settings.

Academic entrepreneurship is a concept typical of a knowledge society. It has gained prominence as knowledge becomes a key to technological, economic, and social growth. Silicon Valley's growth has been the model for Western countries, significantly influenced by academic entrepreneurship at Stanford University. The institution's close ties with industry led to a thriving tech ecosystem. Universities could play a vital role in regional economic development by fostering new businesses, creating jobs, and attracting talent.

Speaking about knowledge entrepreneurship, observers have tried to show how businesses can create, manage, and profit from intellectual capital. Knowledge is the fundamental resource. "The knowledge entrepreneur is based on the ability to communicate, present, or more importantly, apply the knowledge asset" (Skrzeszewski 2006). The rise of this concept is closely linked to policies encouraging universities to contribute directly to economic growth, such as the Bayh-Dole Act (Mowery et al. 2004), which in the United States allowed universities to own and license patents derived from federally funded research. The relevance of the institutional context in promoting the birth and strengthening of entrepreneurship is evident in the case of the United States.

One of the core aspects of academic entrepreneurship in spinoff ventures is the formation of companies, where research outcomes become the basis for new businesses. Faculty, researchers, or even students may form these ventures.

Another relevant aspect of academic entrepreneurship is industry partnerships and funding, including direct alliances between universities and private companies. These partnerships allow academic research to be influenced by real-world needs, which often leads to applied research with direct industry applications.

The entrepreneurship education and training theme is very relevant in almost all European universities. These universities increasingly offer programs focused on entrepreneurship, such as courses and workshops aimed at equipping innovators with the skills needed to launch and manage businesses.

Many universities have created Technology Transfer Offices (TTOs) that are responsible for patenting and licensing research discoveries. The TTOs also support internal staff (e.g., patenting, commercialization process, and creation of spinoff ventures) and external clients (e.g., agreements for adopting innovative technologies, commissioning new research experiences, and licensing/patent assignments).

Research Methodology and Phases

When we started participating in the European project on academic entrepreneurship, we did not intend to carry out research. Over time, we developed the intention to carry out research when we understood that we had discovered something new, thanks to a questionnaire that had initially been conceived only as a means to gather initial information and, at the same time, give a stimulus. The information we saw emerging from the data led us to formulate a research plan that we gradually specified and structured.

From a methodological perspective, the research design combines and integrates desk and field survey tools (Corbetta 2014; Creswell, 2007). Therefore, it is structured into five distinct phases.

The first phase focused on gaining an initial understanding of how young people perceive entrepreneurship and how this perception has evolved over time. This phase began with a desk analysis, using cross-reading of preexisting data (Corbetta 2015a) derived from the last four national research reports by the "Generazione Proteo" Observatory, from 2019 to 2023, encompassing approximately 20,000 students across Italy (Ferrigni 2018). These data were compared with the most established national and international literature.

The second phase, field-based, involved a questionnaire administered to students at the University of L'Aquila. This phase marked a turning point, shifting the project from a simple EU initiative to actual research. The emerging data transformed our approach and led us

toward unforeseen objectives. The third phase, also field-based, adopted a qualitative approach (Corbetta 2015b; Creswell 2009) by analyzing and comparing perceptions across different target groups. This phase involved multiple focus groups with participants including entrepreneurs, students, observers, practitioners, teachers, professors, and policymakers from various universities and cities across Italy. We used a mixed-methods approach to survey young people, including in-person focus groups. Insights from the focus groups were then further explored through in-depth interviews (Corbetta 2015c). We also interviewed families and teachers at length to understand the students' inner mentality better culturally. We suppose this mixed-methods approach allowed us to interpret the survey responses correctly and profoundly.

Thanks to this approach, we got beneath the surface and past the socially acceptable face a student may present when clicking an online form or answering a question over the phone. In the first 10 minutes of our in-depth interviews, students often said they trusted the support for entrepreneurship given by public institutions. By 60 minutes in, as we built reciprocal confidence, many admitted they would leave Italy. They discovered more of their worldview: lack of yearning, frustrations about opportunities, and a sore perspective on the future.

The fourth phase compares conditions in southern Italy with those in the northern regions through additional questionnaires, interviews, and focus groups. The fifth phase compares Italian and European contexts with other countries, primarily China and the United States. Despite political differences, these countries are marked by vibrant entrepreneurial activity and openness that exceeds Europe's. This phase incorporates conferences, meetings, and literature analysis, bringing American and Chinese entrepreneurs and scholars as guest speakers.

The distinction between these research phases is logical rather than strictly chronological. Certain aspects of the research have been developed almost simultaneously; for instance, we made a critical comparison with entrepreneurial China during the intermediate research phase, as this comparative aspect was deemed essential from the outset. Additionally, the European project has been conducted alongside the research, with differing objectives. While the European project promoted university entrepreneurship, particularly among disadvantaged groups, the research focused on examining the variations in entrepreneurial culture within Europe.

Furthermore, some research profiles were active during all the phases; for example, the collaborative relationship with the other four universities involved in the European project has remained constant and decisive throughout the research.

The main result of our research

The initial survey yielded results that were surprising for us in many respects. As foreseen in the European project, we started our work by designing and administering a questionnaire sent to the students from L'Aquila University. The results were so suggestive and unexpected that they led us to more theoretical considerations and an accurate statistical analysis with many tables and graphs that we do not reproduce here for reasons of space and synthesis. To verify the results, the same survey was repeated with another sample of students from the University of L'Aquila. This second group confirmed the results and trends obtained from the first group. Between March 22 and April 18, 2024, 283 people participated in the survey, with women slightly outnumbering men at 56%. The average response time to the questionnaire was approximately 18 minutes. The issues' scope allowed us to delve into the

respondents' mindset regarding the topic. In particular, we developed a collaboration with the Order of the Psychologists of the Abruzzo Region to gain specific support in interpreting these mindsets.

L'Aquila is a city in central Italy but has a tradition that classifies it historically, culturally, and economically as part of southern Italy. The traditional image of entrepreneurship suggests that young people in the Global South lack an entrepreneurial vocation, culture, and tradition. Southern Europe is believed to suffer from a long-standing cleavage (Gammone 2015, 2018). Permanent and dependent employment is considered one of the factors characterizing certain geographical areas in Italy and Europe (Aron 1977). With this perspective in mind, we conducted the survey and gradually refined the analysis through in-depth interviews, focus groups, discussions with teachers, observers, and experts, and a review of sociological literature and other research on the same topics. Notably, the data from the "Generazione Proteo" Observatory, established in 2012, which has periodically involved tens of thousands of young people over the years, were particularly relevant regarding creativity, permanent employment, and training among young generations and were subject to a specific and parallel analysis (Ferrigni 2018; Ferrigni and Spalletta 2021).

Compared to previous knowledge of the subject, this survey has provided new, surprising, and objective elements of understanding on topics that are the subject of various and diverse speculations (including a concealed racism towards Southern Europe, the PIGS, and so on). Notably, the data reveals that 70% of the students interviewed would prefer to pursue self-employment or independent work. This specific component of entrepreneurship is thus very pronounced. It is equally illuminating to note that (for 79.2% of the sample), students expect more support (in the eventual start of their own business) from parents, friends, and relatives rather than institutions considered distant or absent. These two profiles depict a new panorama compared to previous wisdom: entrepreneurial vocation significantly exists even among young people in Southern Italy.

The survey shows that most respondents find it "difficult" to manage a private enterprise; such an endeavor is considered highly "risky." There is consistency in the responses: entrepreneurial work is difficult, thus risky, even if "interesting" (for over 50%). Working "for someone else" is felt more "secure" precisely because engaging in entrepreneurship involves many risks caused by the lack of knowledge, bitterly and consciously acknowledged, and the lack of institutional support. Survey data are highly significant in this regard: there is a strong interest in learning "topics related to starting and managing a business." This response is consistent with the reported lack of information. Only insecurity, lack of information, knowledge, and support push young people to prefer dependent employment (Parsons 1972, 1963). Risk management stands out in the responses: the negative perception of the risk associated with entrepreneurial activity is very high. Paradoxically, in a context of unrecognized opportunities, the love of risk (a factor traditionally necessary and specific to the notion of entrepreneurship) turns into a fear of risk.

Overall, in the sample we studied, a low propensity and lack of interest in starting an entrepreneurial activity emerged; the results show that dependent work is preferred. This is not a contradiction but a logical and coherent consequence. The acute perception of existing obstacles leads to surrender and choosing a different occupational life plan despite having different desires. In fact, a significant degree of propensity for creativity and innovation

emerged among the respondents; for example, the possibility of new methods or tools for work is highly appreciated (Susskind 2020). This creative and innovative drive aligns with the data showing how much students would like to acquire more knowledge related to their future work activities; they want to learn more strategies and techniques to solve complex problems, with a view to satisfactory future activities, to generate solutions to hypothetical work problems (Rifkin 1995). The desire to learn and the willingness to grow are extraordinarily relevant.

Generation Z views entrepreneurship in a sense that aligns more closely with "post-materialism" (well described by Ronald Inglehart and the World Values Survey since the 1970s) than with Keynesian "animal spirits" (which are still alive and active in both the West and the East, albeit framed differently). In short, Generation Z embraces the demand for openness to the new and readiness for change, which are now becoming mandatory. The International Monetary Fund warns that approximately 60% of current work modes risk being erased by the rapid penetration of Artificial Intelligence (AI) in producing goods and services. AI, deep learning, generative intelligence, and a readiness for innovation and entrepreneurship are becoming increasingly necessary and interconnected.

An exciting explanation emerges from our study (closely related to the low motivation and inclination to start a private business): the self-assessed knowledge in innovative work practices, marketing, accounting, social enterprises, and other sector variables is minimal, according to the respondents. Indeed, almost paradoxically, there is a high interest in starting an independent business. However, on the other hand, there is also an enormous lack of information, which could deter the investment of energy and money into this independent venture (Boeker and Karichalil 2002). For example, the respondents would like more knowledge related to business risk, human resource management, legislative information, union issues, banking, and many other aspects of entrepreneurship. In line with the spirit of the times, students prefer to acquire these skills through lectures or preprinted materials and, primarily, through business guides and tutoring, group discussions, and hands-on learning. A business tutor could compensate for the previously mentioned lack of information and, thus, educate and inform students about starting a business. Direct experience is a highly appreciated factor among young people, favored over all other learning methods. The preferred path is hands-on learning through internships, company visits, mentoring, and peer-to-peer interactions. Implementing these training requests would consequently increase students' openness to entrepreneurship.

The most concerning data from the research relates to the obstacles that discourage starting a business. Indeed, in the students' perception, every single hindering factor presented in the questionnaire was seen as significantly invalidating. For example, they believe there is a lack of entrepreneurship education in high school, a lack of university training on the subject, a lack of bank loans, a lack of support from the EU, difficulty in finding suitable staff and partners, lack of knowledge in human resource management, and difficulty in setting up business elements such as a business plan. Few students know what the TTOs are.

Proponing holographic images of nerds like Mike Lazaridis and Doug Fregin, or inimitable pioneers like Steve Jobs and Steve Wozniak, or geniuses who seemingly appeared out of nowhere like Bill Gates and Paul Allen is entirely inappropriate. Today, the Italian (and European) context is very different (Spalletta, Ferrigni, and De Rosa 2024). Through the interviews and focus groups, we found that our students' expectations are socially grounded. In the open-ended responses, for instance, respondents indicated their

preferred future stances as related to activities in the healthcare field, such as private practices or rehabilitation centers and social cooperatives. Outside the healthcare field, small business activities are predicted, including restaurants, sports associations, construction companies, agricultural enterprises, tourism, and various types of startups, including in the engineering sector. Working is still viewed as a fundamental activity that gives meaning to one's life.

The demiurgic notion of entrepreneurship (Magnuson 2024) can be reconsidered in a more sober and realistic light of the challenges posed by the rise of AI. Our project pays particular attention to those discouraged in their studies and lagging behind their peers. The research highlights the relevance of these profiles. The ability of large corporations to generate the future is not the only factor; there is also a social necessity to include a shared vision. Entrepreneurship can also mean shaping a more open and cohesive society that can better meet the needs of its citizens. Pursuing innovation, creativity, and profit does not necessarily imply shared social development.

The sample examined primarily consists of students in healthcare, economic, legal, social, scientific, and technological fields—sectors theoretically well-qualified for entrepreneurial endeavors. Conversely, students in the arts and humanities are underrepresented (only 7.4% of the sample). These students from the University of L'Aquila are mainly expected to pursue careers in teaching. Based on this data alone, one might expect a solid entrepreneurial inclination, but instead, a preference for dependent employment and job security is observed. Interpreting the survey this way would reinforce traditional and detrimental prejudices. However, the creative, innovative, and entrepreneurial spirit is present but clashes with and is stifled by a social, cultural, and institutional context perceived as impoverished, disappointing, and discouraging.

This entrepreneurial project could ultimately benefit young people by showing them the various institutional opportunities (from local to European levels) that are not sufficiently known but can be explored (Supiot 2023). Simultaneously, the project could benefit businesses and institutions by maximizing educational and informational offerings, revealing lesser-known dimensions and information to young people. The aim is to replace the vicious cycle with a virtuous one, which can be activated not through additional economic resources but through constructing a renewed perception.

Most respondents consider themselves on par with their peers' educational competencies and believe they belong to an average economic, social, and cultural bracket. A quarter of the respondents consider themselves part of a disadvantaged group. The numerous responses reinforce the idea that our data are balanced and coherent: The respondents belong to the middle class but clearly want to advance and are very willing to do so, as evidenced by the high percentage of those seeking opportunities. Most respondents have high career and educational aspirations, demonstrated by their desire to pursue a master's degree or a PhD. These social and academic aspirations are seen as steps towards a career once studies are completed. Many of the sample already seek job opportunities during their studies, highlighting a solid desire to enter the workforce. In the interviews, even older individuals showed a strong desire to challenge themselves and start anew, considering the possibility of quitting a dependent job to attempt independent work.

In conclusion, the low inclination to start an entrepreneurial activity is due to the lack of information and training available to students. There is full awareness of this context. Most students have working aspirations and, above all, want to learn more about the

entrepreneurial world. The entrepreneurial spirit exists, but there is also full awareness of the existing opportunities, especially at the educational and institutional levels (Eryaman 2007).

Realizing whether and how to pivot is never easy in the business field. In an interview, an entrepreneur exposed the relevance of the educational and institutional context (Cohen et al. 2007), citing almost literally the *Law of Requisite Variety*: "In a game, the variety possible is determined by the number of possible choices open to the players" (Ashby 1956). In his opinion, the variety of opportunities offered to young people living in poor institution contexts gravely limits the number of possible choices open to them.

Various research hypotheses exist on inequality in young people's perceptions. The critical issue that emerges most clearly in students' perceptions (and is confirmed in the opinion of their teachers) is the meaning of diversity linked to economic inequality and the socio-cultural context, which young people identify as the origin of spaces of individual and social vulnerability. This vulnerability generates educational poverty that young people perceive as a factor of social exclusion.

Entrepreneurship and Southern Europe

This European project involves the University of L'Aquila and several other universities in Southern Europe, including those from Bulgaria, Romania, Türkiye, and Malta. It is said that Southern Europe has a different entrepreneurial and economic mentality compared to the rest of Europe, particularly countries like Germany or Northern Italy. Our research has already yielded a significant result: we have found a powerful entrepreneurial vocation among Southern young people. However, this vocation is unlikely to be realized because these same young people believe that there are no social or economic institutions, either informational or educational, that provide opportunities for their entrepreneurial spirit to flourish (Ricolfi 2019).

This is already the best result of our research, which echoes concerns recently highlighted by the governor of the Bank of Italy, Fabio Panetta: hundreds of thousands of young people (especially in the South) are leaving Italy, and there is a decline in small and medium-sized businesses that had been the backbone of the Italian Miracle. Many Southern European countries have similar problems (Gammone, Sidoti 2012). We have compared this situation with China and the United States. The two countries are very different but have a fundamental point in common: outstanding, thriving, and unique entrepreneurship. In comparison, not only southern Europe but the whole of Europe is very different.

As our interviews and reading of the classics on the subject have shown, entrepreneurship does not arise only from an idea but, above all, from an institutional, social, and economic network that allows the seed of that idea to germinate and grow, transforming itself into a plant and its fruits.

Entrepreneurial success is often more about innovation, experimenting, and learning. "Trial and error" is a fundamental problem-solving method characterized by repeated, varied attempts that are continued until success. Before finding that formula, C. Lloyd Morgan used phrases like "trial and failure" and "trial and practice". Gary Shapiro, the president and CEO of the Consumer Technology Association, explored the conditions under which a company's existential crisis shifts in gears. In his many books, he has described the epic story of how many American companies have failed and then resurrected, bringing extraordinary innovations that will profoundly transform our development model in the

future and that already significantly impact our lives. Writing on the era when first integrated podcasts disrupted the startup Odeo, he says: “If you’ve checked Facebook or LinkedIn, watched a show on Netflix, traded stocks on Robinhood, placed a bet on Sportsbet or DraftKings, or ordered lunch on DoorDash, you’ve benefited from a pivot that reinvented the way we use the internet.” (Shapiro 2024)

Our research found that southern Italy's case is consistent with what happens in almost all southern Europe. The topic of entrepreneurship in Italy shows delays and obstacles, as recently highlighted by the study *It's all about IT*, conducted by Mediobanca Research and explicitly devoted to the issue of the mid-caps: "Italian companies do not lack available means... A cultural factor emerges instead." Notably, similar notations are present in the data coming from the "Generazione Proteo" Observatory.

We have inserted our local cultural search within the broader framework of entrepreneurship's history and peaceful exchange relations in the Eastern and Western past. The difference is striking nowadays; for this reason, it can teach us some lessons. On the relevance of free trade and general social conditions, it is sufficient to refer to the fundamental works of Fernand Braudel.

In a certain sense, this study is an extension and precision of many other studies we have conducted over the years on parallel or neighboring themes. In research conducted in Bulgaria, Türkiye, and Romania, we found challenges and issues similar to those observed in Southern Italy. Of course, each country has different institutional contexts and industrial and commercial traditions. In Çanakkale, for instance, according to survey results, the average preference for working in small, medium, and large-scale enterprises is above 60%. Participants highlighted the value of universities in fostering entrepreneurship. Students demand support for their entrepreneurial skills and emphasize the necessity of education on entrepreneurship (Angelova M. et al. 2024b).

In Southern Europe, young people think that entrepreneurship should be more significant in national policies. They hope that universities and businessmen must work together to develop new policies and training programs. This open mindset and availability should be included in the broader reflection on the condition of young people in these countries (Eryaman et al. 2011).

The term entrepreneur implies an entity that can translate inventions or technologies into products and services. In this sense, it identifies new business activities (Gammone 2021). Information innovation and technology are crucial opportunities for knowledge entrepreneurs (Coulson-Thomas 2003).

In the USA, many lament government efforts to rein in Big Tech. To them, an “over pivot” has been catastrophic for American innovation **(**Etzkowitz 2002). Many claim that even behemoths like Apple and Microsoft "started in a garage." These criticisms often confuse suffocating public dirigisme with an adequate institutional context of proper rules and efficient public administrations. Some regulations have helped consumers and empowered innovators. A frequently cited example is the antitrust lawsuits against Microsoft in the 1990s, which helped engender the rise of Google. Not only students but all people could be helped to pivot. An adequate institutional context must help not only students and young people but all people to adapt to the tumultuous wave of technological novelties. All people must be helped to pivot. A new world is coming thanks to the vast expansion of internet connectivity and rapid improvements in data-transfer technology (Shapiro 2011, 2013). In this sense, helping the development of an entrepreneurial mentality

means developing the general ability to adapt to rapid, surprising, and demanding change and profit from it instead of being overwhelmed. "There is an attendant need to organize and package information for users, to put the information in context, to provide information intermediaries and facilitators, and to digitize all forms and formats of information – all major entrepreneurial opportunities" (Skrzeszewski 2006).

Entrepreneurship is a multifaceted concept shaped by economic, behavioral, opportunity-driven, resource-based, psychological, and sociological perspectives. As global challenges evolve, these definitions continue to grow, broadening our understanding of what it means to be an entrepreneur and its impact on economies and societies. Academic entrepreneurship is crucial in fields like biotechnology, where university research often leads to rapidly commercializing breakthroughs, as seen with advancements in genetics and pharmaceuticals. A concern is the risk of shifting academic priorities. Some argue that an excessive focus on commercialization could undermine basic research, which is essential for long-term progress but may yield little economic returns (Shane 2004). By bridging the gap between science and industry, academic entrepreneurship enables universities to serve as engines of innovation.

The global "right path" must be found and followed in a context of mutual respect. Like academic entrepreneurship, many other areas are conducive to convenient intercultural encounters. Acemoglu and Robinson are right: the greatness of nations depends on their ability to be "inclusive", that is, open to opportunities and sharing, innovation, and redistribution. Nations fail if they are "exclusive" or "extractive," closed in managing wealth and power by a few intimates. The Popperian theme of the "open society" is also central to entrepreneurship, as is the relevance of institutions.

Conclusion

Academic entrepreneurship, the commercialization of innovations within universities and research institutions, has gained prominence in the knowledge society. Universities play a vital role in regional economic development by fostering new businesses and attracting talent.

This study underscores the crucial role of institutional contexts in shaping entrepreneurial behavior of students at the higher education institutions. Students' perceptions of limited opportunities and support, coupled with a fear of risk, discouraged them from pursuing entrepreneurial ventures.

This finding highlights the need for greater investment in entrepreneurship education and training, as well as policies that foster a more supportive environment for young entrepreneurs. While this research study provides valuable insights into the perceptions and realities of entrepreneurship among young people in Southern Europe, it is essential to acknowledge its limitations.

Firstly, the sample is limited to university students, and the findings may not be generalizable to the broader population of young people in these countries. Secondly, the research is cross-sectional, and future longitudinal studies could provide a deeper understanding of how perceptions and aspirations evolve over time.

This study highlights the fundamental role of universities and educational institutions in bridging the gap between students' entrepreneurial aspirations and the perceived institutional realities. By providing the necessary support, knowledge, and resources, universities can empower students to pursue their entrepreneurial dreams and contribute to

economic growth and social development. Further research is needed to explore the specific factors that contribute to the perceived lack of institutional support and to develop effective strategies for fostering a more entrepreneurial culture in Southern Europe.

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Original Article

Public Perspectives on Introducing Sex Education in Romanian Schools: A Quantitative Analysis

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Abstract

Many international organisations agree that sexuality education is a useful topic for the development and well-being of students and society, as they have the right to receive safe and scientifically based information to prevent and combat aggression and possible sexually transmitted diseases. However, the introduction of sex education into the curriculum in Romania has been heavily debated in recent years, with negative opinions from religious and political leaders at the forefront.

This research approaches the topic from a quantitative perspective in which the sociological survey was used as the research method, with the research instrument being the survey. The survey also included a number of open-ended questions so that qualitative information could be collected and analyzed. The main aim of this article is to capture the general opinion of parents and adults regarding the introduction of sex education in schools and to identify their possible fears related to the content of this education. The research question we want to answer is: "What is the opinion of adults and parents about the introduction of sex education in schools?"

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The survey was conducted over a two-week period (May 2023) and comprised a series of 29 questions with different answer options. For this study, we used a group of 518 respondents who were analyzed by gender, age, religion, origin and last completed education. The survey was created in Google Forms and sent online via various social networks. We can therefore not speak of a representative sample, but rather of a random sample, but the relatively large number of responses collected, namely 518, allows us to test the hypotheses, but not to generalize. When analyzing the respondents' answers (using Microsoft Excel), surprising results were obtained that are consistent with the data from the literature, but also in contrast to some recent studies. To summarize, despite the controversial political and religious information circulating in the public sphere today, the majority of adults and parents who participated in our survey believe that sex education should be included in the school curriculum. The results of this survey were unexpectedly promising for the future of Romania, but unfortunately, we cannot generalize them. Respondents want this topic to be taught as early as possible and believe that it will help students to become responsible adults.

Keywords: sexuality education; educational system; national curriculum; sociological survey; health education.

Introduction

First and foremost, sex education is health education. In this subject, children learn many important things for their lives, such as: the responsibilities and risks of sex, information about gender equality and sexual orientation, maintaining healthy interpersonal relationships, and the ability to say "no" and protect their physical and mental health. In addition, sexuality education is essential to prevent and combat child sexual abuse, sexual exploitation and sexual violence (Schneider, M., & Hirsch, J. S., 2020; Wurtele, S. K., & Miller-Perrin, C., 2017). Another very important aspect that can be addressed in the curriculum of this subject is the prevention of gender-based violence and discrimination against women (Rollston, R. & al., 2020; Goldfarb, E. S., & Lieberman, L. D., 2021). All of this information would keep children away from sexually transmitted diseases and unwanted pregnancies from a young age.

Unfortunately, in Romania, topics such as the effects of sexual contact, the rights of the child in relation to his or her body and sexuality, and sexually transmitted diseases are still taboo (Rada, C., 2014; Iorga, M. & al., 2021; Costin, A., 2021). These, in turn, fall under the child's right to be informed and healthy (Bialystok, L., 2018) and to defend themselves in the face of imminent danger. Young people and children have the right to receive all scientifically sound information on sexuality education (Helmer, J. & al., 2015).

About sexual education. Conceptual foundations & state of the art in several EU countries

Overall, evidence collected in randomized control trials has shown that sex education programs have positive effects on sexual health behaviors, including risk reduction, delayed onset of sexual intercourse (Guse, K. & al., 2012; Mathews, C. & al., 2012), increased contraceptive and condom use (Hindin, M. J. et al., 2016; Fonner, V. A. & al., 2014) and a low number of sexual partners (Montgomery & Knerr, 2016; Picken, N., 2021)

According to UNESCO and WHO, effective sexuality education should take a comprehensive approach, i.e. a process based on a school curriculum that includes information on the cognitive, emotional, physical and social aspects of sexuality1. Sexuality education programs can address a wide range of topics such as sexual and reproductive health, relationships, sexual orientation, and gender roles. (Picken, N., 2021; WHO and BZgA, 2010).

Research suggests that school-based sexuality education programs influence not only risk behaviors, but also health knowledge and attitudes (e.g., students' knowledge about the importance of contraception) (Lopez, L. M. & al., 2016). However, although there are fewer randomized control trials or reviews directly linking sex education programs to improved biological outcomes (such as teen pregnancy, sexually transmitted infections, or lower rates of human immunodeficiency virus-HIV), there is a consensus that the introduction of sex education in schools does not lead to an increase in sexual activity, risk behaviors, or STI (sexually transmitted infection)/HIV infection rates among young people (Shepherd, J. & al., 2010).

A number of studies have also found that programs that include active student skill development and involve medical staff and parents in implementation are more likely to change student behavior than programs that are solely school-based and focus on information sharing (Kirby, D. B & al., 2006). Recent research also suggests that programs that adopt educational interventions that have been shown to be effective elsewhere are more likely to improve student knowledge and behavior, even when replicated in other contexts, countries, or cultures (Gardner, F. & al., 2016).

Beyond health outcomes and knowledge, there is also emerging evidence that sexuality education programs can contribute to broader social change. Sex education programs that have a gender-specific or skills-based focus have been associated with outcomes such as reducing the risk of child sexual abuse (Bundeszentrale für gesundheitliche Aufklärung - BZgA, 2016), establishing equitable gender norms and increasing self-confidence (Unterhalter, E. & al., 2014), and strengthening young people's relationship skills. However, this evidence currently comes from qualitative, non-randomized, uncontrolled studies where it is difficult to attribute causality (Montgomery, P. & Knerr, W., 2016).

UNESCO suggests a number of key concepts for successful sex education, as follows (Picken, N., 2021): 1. Relationships; 2. Values, rights, culture and sexuality; 3.

Gender identity; 4. Violence and how to be safe; 5. Health and wellness practices; 6. The human body and its' development; 7. Sexuality and sexual behavior; 8. Sexual and reproductive health. For each key concept, UNESCO identifies important topics and objectives to be addressed for each age group from 5 to 18 years.

Examples of Sexuality Education in European countries

In *Ireland*, sexual and reproductive education is compulsory and is offered as part of the Social, Personal and Health Education (SPHE) curriculum. According to the 2018 IPPF report, teaching focuses heavily on biological aspects, with an emphasis on risk prevention by encouraging abstinence and the prevention of STIs and HIV (Ketting, E. & Ivanova, O., 2018).

In *Austria*, sexuality is seen as an important part of children's overall development and sexuality education aims to support children in ensuring their physical, cognitive and emotional sexual health (Kapella, O., & Mazal, W., 2022). Therefore, sexuality education in Austria is considered comprehensive by NGO representatives and is designed in accordance with WHO standards. The curriculum focuses on biological aspects and the prevention of early pregnancy and STI/HIV, but also covers topics related to sexual identity, mutual consent, social internet and gender-based violence (Ketting, E. & Ivanova, O., 2018).

The *Netherlands* and *Denmark* are leaders in sexuality education among industrialized nations. In the Netherlands, children are educated about sex from the age of 4. According to the PBS website, children learn how to form relationships and talk about sexuality. The Dutch philosophy is to promote respect for all sexual preferences and to help students develop protective skills against coercion, intimidation and sexual abuse (PBS NewsHour, undated).

Sweden is a well-developed country in terms of sexuality education (Tydén, T. & Rogala, C., 2004). In 1955, it was the first country to introduce sex and gender education as a compulsory subject. Since then, Sweden has constantly updated its curriculum on the subject to keep pace with changes (Ekstrand, M. et al., 2011).

However, despite the progressive approach to sex education, a 2011 survey found that 96% of Swedish students and graduates were dissatisfied with the treatment of sexual assault in schools and that they had learned very little about sex in sex education classes. Students also said that they did not receive enough information about gender issues (Avery, L. & Lazdane, G., 2010).

Brief history regarding the implementation of sex education in Romania. Obstacles and prospects

As we emphasized above, sex education is a compulsory subject in the curriculum of most European countries. In Romania, however, it is only optional and, according to statistics, at most 10% of children enrolled in school benefit from this subject (Mihăilă, L., 2023).

In April 2020, the draft law "Health Education in School", initiated by the USR / Uniunea Salvați România MP Cristina Iurișniți, was promulgated, which provides that students benefit from this subject at least once per semester (USR, 2020).

In June 2020, the term "sex education" was removed from the law and replaced by "health education" and this education can only be provided with the written consent of parents. President Klaus Iohannis declares that the manner in which this project was adopted violates the Constitution and calls for a reconsideration. In this request for reconsideration, the President states: "... Health education programs are emphasized only through health education, eliminating the sexual health education component or simplifying it to only the transmission of personal hygiene information. The idea of health education is outdated and no longer reflects the current concept of public health. The concept of health education used before 1990 only included "hygiene activities". At the end of 2020, Romanian President Klaus Iohannis called for the review of the Law on the Protection and Promotion of the Rights of the Child, in particular the renaming of health education to "sexual education", which was rejected by the Working Committee of the Romanian Senate (Roșca, I., 2021).

According to a press release, the USR PLUS party requested at the meeting of the Labor Committee the deletion of the article of the law that renames the term "sexual education" to "health education", the abolition of parental consent for participation in these classes, the beginning of sex education classes in the 5th grade, and the introduction of a new term "health education". Obviously, these changes were rejected (Roșca, I., 2021).

This motion came into the debate exactly in the middle of 2021, when senators from the National Liberal Party (PNL), the Social Democratic Party (PSD) and the Democratic Union of Hungarians in Romania (UDMR) voted against this amendment and a PSD senator stated the following: "We managed to reject Iohannis' motion. This man really wants the practice of masturbation to be taught to children from an early age in schools." (Roșca, I., 2021).

Obviously, the Romanian Orthodox Church played a very important role in the final decision. This measure hinders Romania's development when it comes to reducing the incidence of sexual abuse and unwanted pregnancies, as well as homophobia. Furthermore, the Romanian Orthodox Church's involvement in this issue makes no sense and is downright ironic, especially considering that many priests have been accused and punished for sexual abuse and harassment (Digi 24, 2022; Palade, M., 2021).

The Romanian Orthodox Church declared that sexual education is "an attack on the innocence of children, which hinders their natural development and shapes them for life" and further states that NGOs are "apostles of the sexualization of children's lives from the earliest possible age". Moreover, the Romanian Orthodox Church attests that the WHO's claims are "despicable" and that the data according to which Romania is the leader in the number of underage mothers in the EU are in fact manipulated (Fati, p., 2022).

In June 2021, the Minister of Education Sorin Cîmpeanu mentioned that sex education is taught in schools as part of an optional course, but he also said that only about 6% of students take part in it. However, the documents show that this optional course/lecture is attended by 148,500 students, which is about 7% of the total number of students in Romania (Roșca, I., 2021). As mentioned in the article, the elective subject "Education for Health" was included in the curriculum in 2004 and is taught in 2240 schools in Romania, more precisely in 1294 schools in rural areas and 946 schools in urban areas. The curriculum of this optional class included family roles and the differences between girls and boys for 1st and 2nd grade students, perceptions of girls and boys, puberty and childbirth for 3rd and 4th grade students, attachment and love for 5th and 6th grade students, sexual behavior, sexuality, sexuality and sex education for 5th and 6th grade students. For high school students, the lessons included information on sexual behavior, family planning, STDs, pregnancy and abortion, sexual dysfunction, sexual identity and orientation, pornography and prostitution. Regarding the fact that parental consent is also required for this discipline, the former minister explained that "parental education is therefore also necessary" (Roșca, I., 2021).

In May 2022, Sorin Cîmpeanu, the former Minister of Education, announced that the subject "Education for Life" would be introduced for middle and high school students from September 2023. This subject was to include a module on sex education, from which parents could opt their children out by submitting a written request (Edupedu, 2022).

In June 2022, following a vote in the Chamber of Deputies, sex education will be introduced under the name "Education for Life" or "Health Education" precisely from the 8th grade and only with parental consent (Popescu A., 2022).

It is disheartening that students in 8th grade come into contact with this topic for the first time, especially considering that 22.5% of teenagers start their sexual life before the age of 15 and 8% of women who give birth in Romania are also under the age of 15, according to a study by Cult Market Research (Neagu, A., 2022).

A member of parliament from the Alliance for Romanian Unity (AUR) party, who was against the introduction of this issue, explains: "We need freedom, not ideology, we need the freedom to decide how we raise our children. We do not need child masturbation, gender ideology, abortions among teenagers, sexualization of children. This education should be based on some healthy concepts, they should be encouraged to reduce the need for physical attraction by playing sports, all kinds of dangers that exist in the digital environment related to these aspects" (Popescu A., 2022).

In March 2023, an article published on the edupedu.ro website states that the Minister of Health Alexandru Rafila claims that the subject "health education" must exist as a compulsory subject in schools and include appropriate content for all ages: "As long as we do not introduce health education as a compulsory subject in schools, we will not make progress in many areas, including the area of unwanted pregnancies. After all, health education is not just about sex education, it is a concept that must be taught by teachers trained for this, adapted to the age of the child. As long as only 5% of parents send their

children to health education, which is an optional subject, and only 2% of these children complete the health education modules, we will not make any progress" (Edupedu, 2023).

Materials and methods

In this study, we wanted to analyze the opinions of adults and parents about the introduction of sex education in schools. In our study, we wanted to find out if people are really against the idea of sex education, an idea that is very common in the political and religious space. We also wanted to find out whether there are contradictory views among the respondents.

The main purpose of this study is to capture the general opinion of parents and adults on the introduction of sex education in schools and to identify their possible fears related to the content of this education. The research question we addressed is: "What do adults and parents think about the introduction of sex education in schools?". The general aim of this study is therefore to find out the general opinion on this subject. The specific objectives are to determine the relationship between socio-cultural and biological factors and respondents' opinions about the introduction of sex education in schools and to identify the presence of fears related to the content of this topic.

With this quantitative study, we aim to verify the following statements:

The majority of respondents are in favor of introducing sex education in schools, regardless of opinions from the political and religious sphere

The majority of respondents believe that sex education is necessary to prevent unwanted pregnancies, despite their religious beliefs

The majority of respondents think that sex education should be taught by people trained in this field or by medical staff

The majority of respondents are of the opinion that sex education should be taught weekly

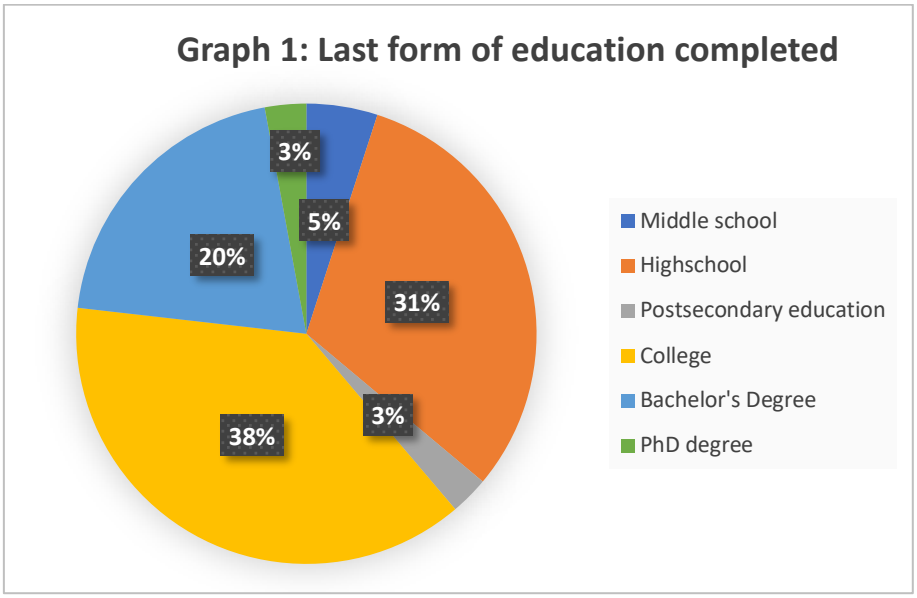
Compared to men, more women would like sex education to be introduced much earlier.

518 people over the age of 18 took part in the survey. The questionnaire also contained a number of open-ended questions that led to qualitative data. The survey was developed in Google Forms and later the data was processed in Microsoft Excel. It was sent online via various social networks, so we cannot speak of a representative sample, but rather of a random sample, but the relatively large number of responses collected (518) allows us to verify the 4 statements, but not to generalize.

The survey was conducted over a two-week period and comprised a series of 29 questions with different response options. In this study we used a group of 518 respondents split by gender, i.e. 399 female respondents, 98 male respondents, 11 non-binary people, 8 fluid people, one she/her person and one demi-girl person. The respondents were between 18 and 70 years old, most of the respondents were between 20 and 30 years old (235 people) and most of them came from an urban environment (454 people). Of the 518 respondents, most are Orthodox (337 people), 396 are single and only 112 have children. The majority of

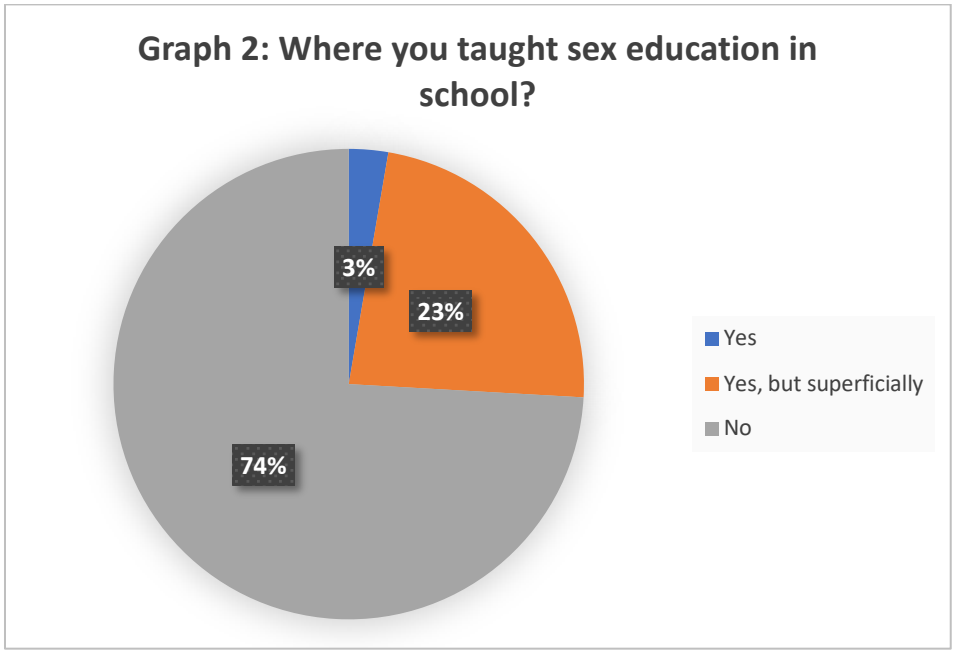
respondents stated that they either had no children or that their children were not yet at school (422 respondents).

Based on the criteria listed above, we have statistically distributed the respondents in the form of diagrams, as you will see below.

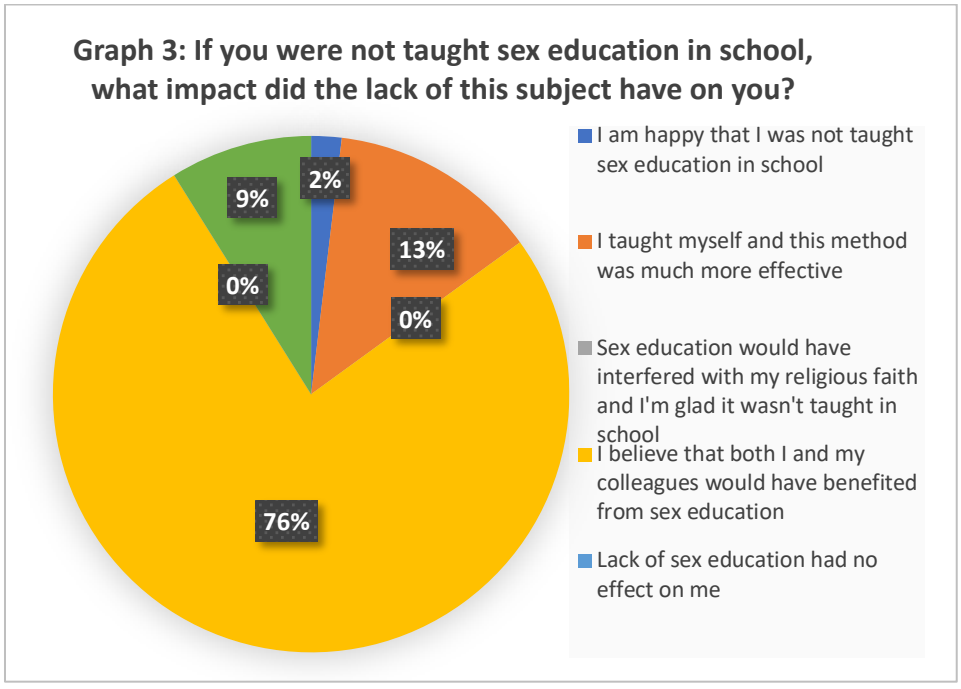


Graph 1 shows the most recent education completed by the respondents. This shows that most respondents have a college degree (38% - 197 respondents).

It should be noted that about 61% of respondents have a higher level of education (college or more) – an overrepresentation in our sample compared to the total population (in the total population of Romania, this proportion is 16.0% according to 2021 Census/RPL data). It is to be expected that a population with a higher level of education is much better informed about sexuality education and much more open to the introduction of sexuality education in schools as a compulsory subject.



Graph 2 shows that the majority of respondents 74% (383 respondents) did not receive any sex education at school, 23% (119 respondents) confirm that they were only taught superficially and only 3% (14 respondents) of respondents state that they were taught properly.



In correlation with Graph 2, Graph 3 analyzes how the lack of sex education affected the respondents. As can be seen, the majority of respondents 76% (394 respondents) believe that they would have benefited from sex education, both themselves and their peers, 13% (68 respondents) believe that it was much more effective to teach themselves, 2% (10 respondents) are satisfied that they did not receive sex education at school. None of the respondents stated that this topic clashed with their religious beliefs.

In contrast, 9% (46 respondents) answered this question voluntarily. You can read some of their answers below:

- "I taught myself, but my family also played an important role by talking to me about sexually transmitted diseases and sexual intercourse."

- "I am afraid of sexual intercourse and find it disgusting, there are many factors that I am not aware of, although I have educated myself about it."

- "No effect. Although I come from an orthodox (practicing) Christian family, I was taught about sexuality at home by my mother. If my mother had not talked to me about this topic, it might have been more difficult as a teenager."

- "We were "taught" sex education by a girl from a pro-life NGO. The information was laced with religion, morality and anti-abortion just to scare us into starting our sex lives as late as possible, preferably after marriage. I was very disappointed and think it would have been better if she hadn't taught us anything at all."

- "When I hit puberty, I knew nothing about myself, my body and my health, things I had to find out for myself by researching on the internet. Had I been educated about these things, I would have been spared the toxic relationships, the contraceptives prescribed far too early by an endocrinologist, or the shame I felt when exploring my body."

- "For a long time in my teenage years, I did not know what consent and sexual assault were, things that I think are absolutely necessary for a teenager to not reach an old age and struggle with trauma."

- "I did not know about the HPV vaccine, even though it was available when I was the appropriate age."

- "I educated myself, I still do, but I can never guarantee that I am well informed."

- "I was lucky with my parents, especially my mother, who explained everything about sexual relationships, diseases, protection, etc. to me from an early age. At the moment I think few teachers would be able to actually teach such a subject; I think it would be a subject like engineering, drawing etc. Sad but true."

- "I was put in situations where I lacked information and did not know what to do."

- "I educated myself, but I learned a lot as an adult. It would have been helpful to know the concept of "care' or practices of wellness, health and sociocultural factors, because that way I might not go to therapy because I am afraid to enjoy something natural."

- "I would have taken my personal health more seriously if we had learned about it. Some diseases are incurable and can affect your quality of life in general."

- "I had a completely wrong idea about sexuality and I believe that with some basic sex education I would have been able to avoid toxic relationships."

- "I had to find out for myself what sexually transmitted diseases meant and that some can overcome the condom barrier. I had to learn on my own that sex does not have to be painful."

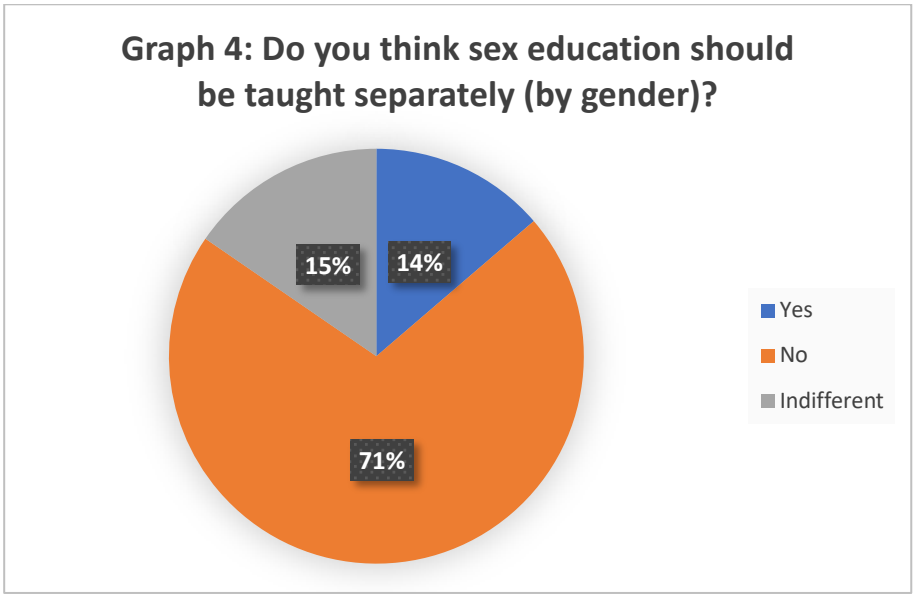
In analyzing these responses, we identified seven main themes: 1) Self-enlightenment: many respondents mentioned teaching themselves about sexual health due to a lack of formal education; 2) The role of the family matters, some respondents were educated by their families, while others noted that this was not the case; 3) Misinformation and fear as common consequences of inadequate education; 4) Trauma and mental health, as several respondents mentioned having experienced trauma or needing therapy due to a lack of knowledge; 5) Cultural and religious influence carries significant weight as religious-based teachings led to frustration for some; 6) Health consequences resulting from gaps in knowledge on health topics such as the HPV vaccine, sexually transmitted diseases and consent; 7) Toxic relationships cited by some respondents who linked lack of education to difficulty forming relationships and avoiding abuse.

The general mood regarding the lack of education is rather negative, with frustration, regret and fear being the predominant feelings. A few respondents expressed neutral or even positive experiences when the family filled the gap.

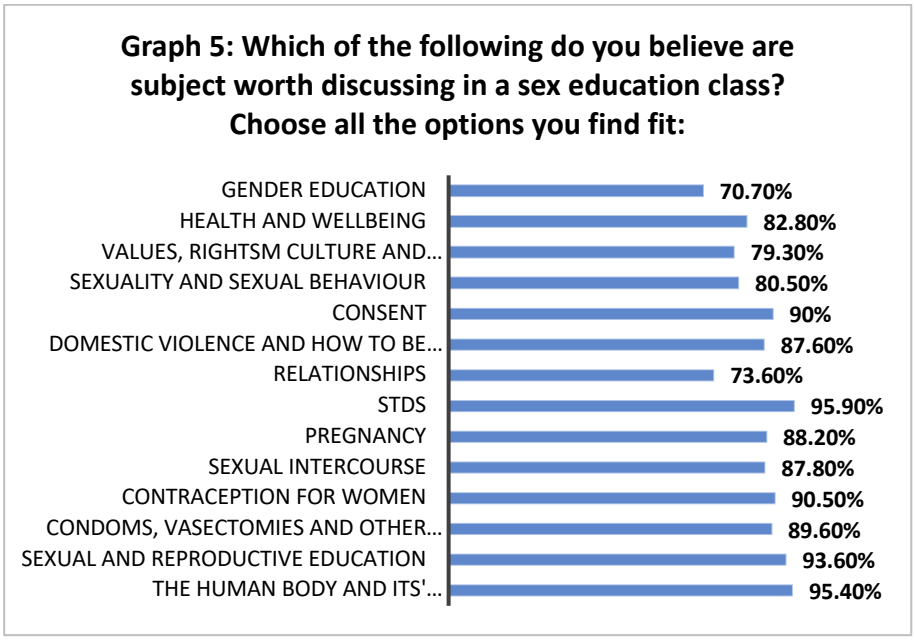
There is a clear need for comprehensive education as many responses indicate gaps in understanding of key issues such as consent, health practices and socio-cultural factors. Reliance on the family for education leads to inequalities, so the role of the family is crucial but unequal. Respondents criticized education that is guided by religious or moral imperatives and indicated a preference for unbiased, factual information. We can also conclude that formal education could prevent trauma related to grooming, consent issues and toxic relationships.

The next image shows the visualization of the word cloud of the answers about the lack of sex education. It highlights the most frequently mentioned words and topics.

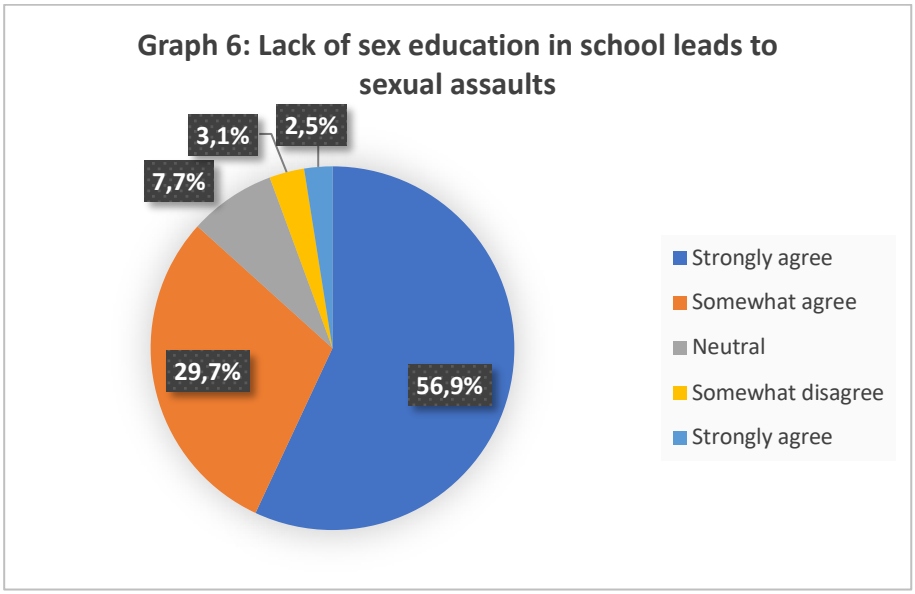
In addition, in Graph 4 we have correlated the above information with the respondents' opinion of teaching by gender. Thus, 71% (367 respondents) think that it should NOT be taught by gender, 14% (71 respondents) that it should be taught separately, and 15% (80 respondents) are neutral.



Graph 5 shows the opinion of the respondents on which subjects they find fit to be discussed in a sex education class.



Remarkably, all themes achieved at least 70% agreement, showing strong general support for a comprehensive approach to sex education. This suggests that respondents see all of these topics as relevant and valuable for inclusion in the curriculum, even if some of them have higher priority than others. Among the topics with high agreement, we find „STDs" (95.90%) and „The human body and its functions" (95.40%), reflecting an almost unanimous consensus on their crucial importance, as well as some other categories that show a strong preference for practical, health-oriented knowledge (sexual and reproductive education - 93.6%; contraception in women - 90.5%; agreement on sexual intercourse - 90%). Moderate agreement topics such as pregnancy (88.20%), sexual intercourse (87.80%) and domestic violence and how to protect yourself (87.60%) emphasize the importance of safety, relationships and reproductive health. Broader aspects such as health and well-being (82.80%) and sexuality and sexual behavior (80.50%) indicate that the emotional and psychological dimension of sex education is supported. Although gender education (70.70%) received the least support, it shows that a clear majority of respondents consider it important.



Graph 6 shows the respondents' opinion on the connection between a lack of sexual education and sexual assault. Thus, 56.9% of respondents (295 respondents) fully agree that the lack of this topic leads to sexual assault, 29.7% (154 respondents) partially agree, 7.7% (40 respondents) are neutral, 3.1% (16 respondents) partially disagree and 2.5% (13 respondents) do not agree at all.

The high level of agreement (86.6%) underscores that the public (at least in our sample) recognizes sex education as an important tool for preventing sexual violence. There are certain implications for the sexual education curriculum, such as teaching about consent (clear understanding of boundaries and respect), recognizing abusive behavior and how to seek help, as well as raising awareness of the consequences of sexual violence and promoting respectful relationships. The 5.6% who disagree reflect a different view, perhaps based on a belief that other factors (e.g. societal norms, education) play a greater role in preventing sexual violence.

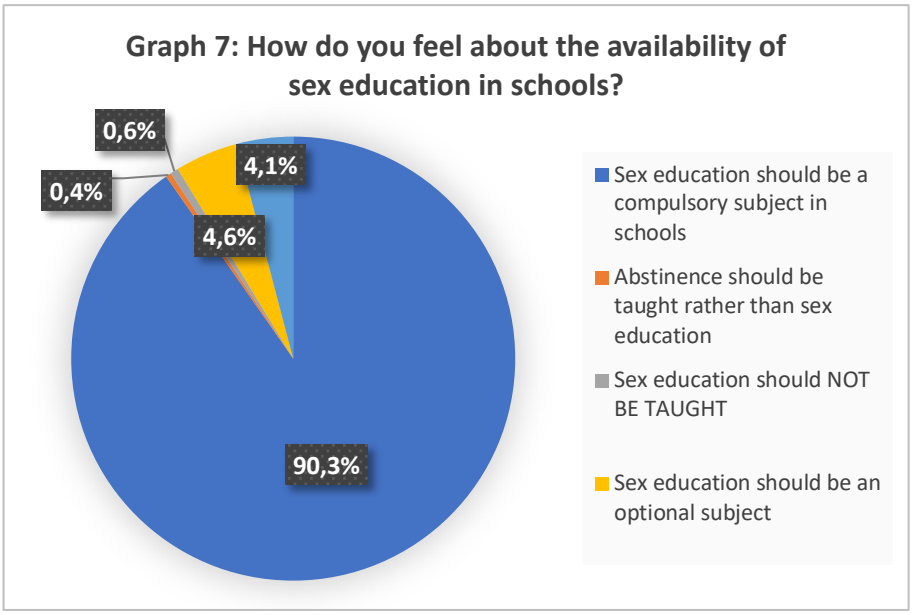
As you can see, respondents' opinions on this statement were more divided than the others. However, a 2018 study linked a lack of sex education to higher rates of sexual assault. Additionally, students who received sex education in schools had a lower risk of being sexually assaulted in college (Neagu, A., 2022).

Results

It was not possible to test some hypotheses statistically, but we did try to see to what extent the opinions of the study participants were convergent or divergent.

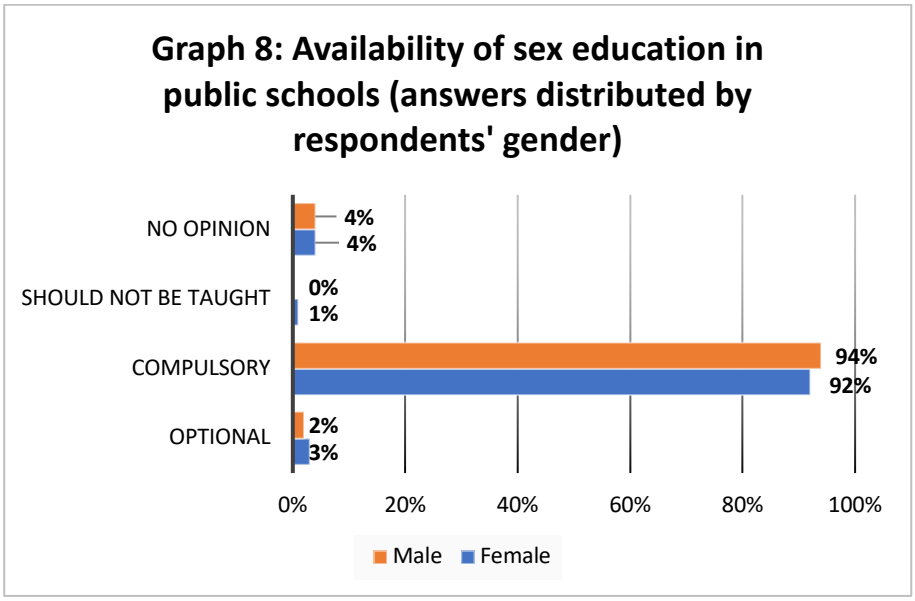
Thus, with regard to the statement "*The majority of respondents are in favor of introducing sex education in schools, regardless of opinions from the political and religious sphere*", it was possible to show that the majority of respondents really are in favor of

introducing this topic into the school curriculum, despite the information in the public domain. This finding is consistent with a study conducted by Cult Market Research for the Society for Contraceptive and Sexual Education (SECS). In this study, it was shown that 77% of Romanians want sex education to be taught in schools, regulated for each age and stage of growth (Neagu, A., 2022).

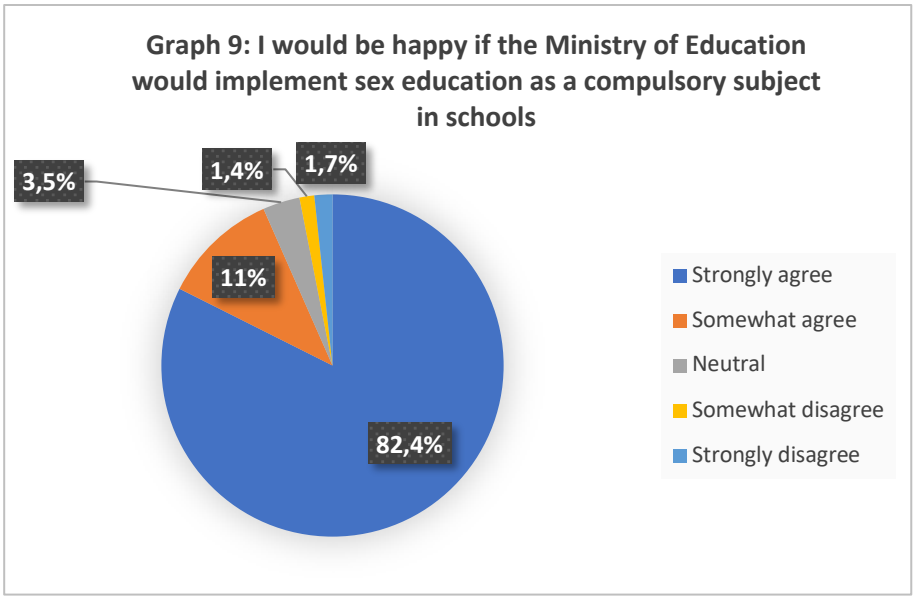


Analysis of the responses to Chart 7 revealed that 90.3% of respondents – the majority (468 respondents) - want sex education to be a compulsory subject in schools, 4.6% (24 respondents) think it should be optional, 4.1% (21 respondents) are neutral, 0.6% (3 respondents) think it should not be taught at all, and 0.4% (2 respondents) want an abstinence-based approach to teaching.

A 2011 study by Stanger-Hall &Hall also found that in US states where sex education only covers abstinence, there are higher rates of unintended pregnancies and sexually transmitted diseases (Santelli, J. S. et al., 2018).

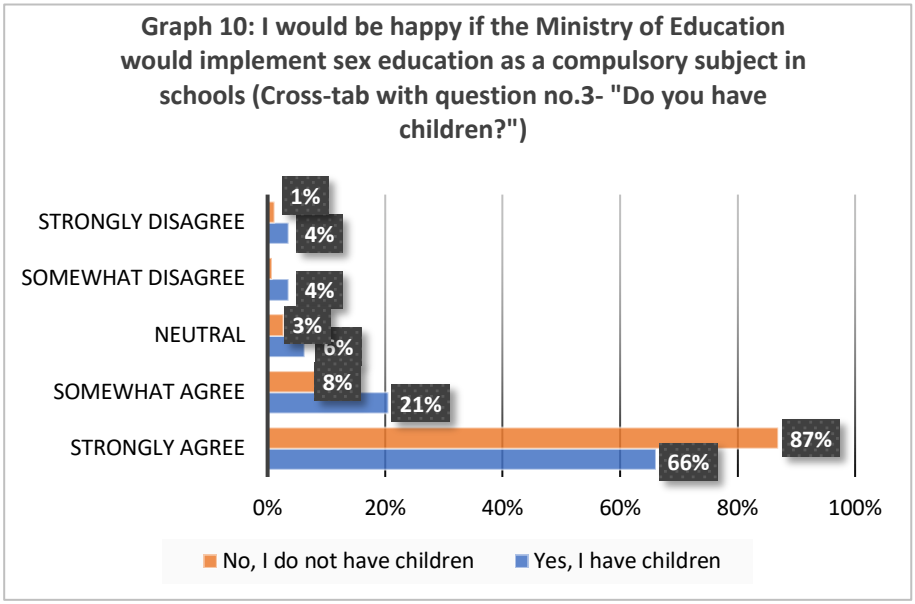


An analysis of the gender-specific distribution of responses to this question shows that 92 out of 98 men (94%) and 364 out of 396 women (92%) are in favor of the mandatory introduction of sex education in schools (see Figure 8). However, the number of male respondents is significantly lower, so we cannot consider this result to be statistically relevant.

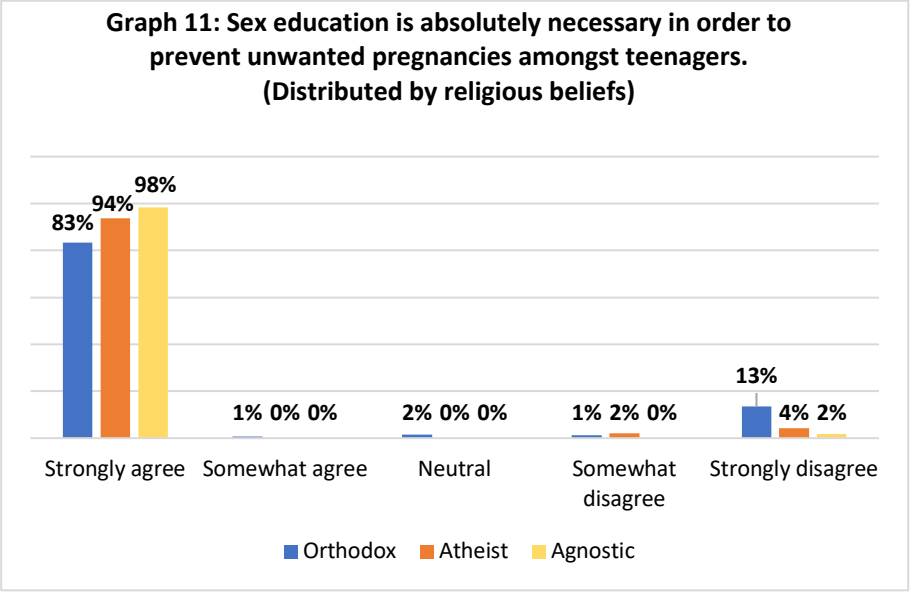


These conclusions were confirmed by the analysis of the answers to question no. 18 („I would be happy if the Ministry of Education would introduce sex education as a

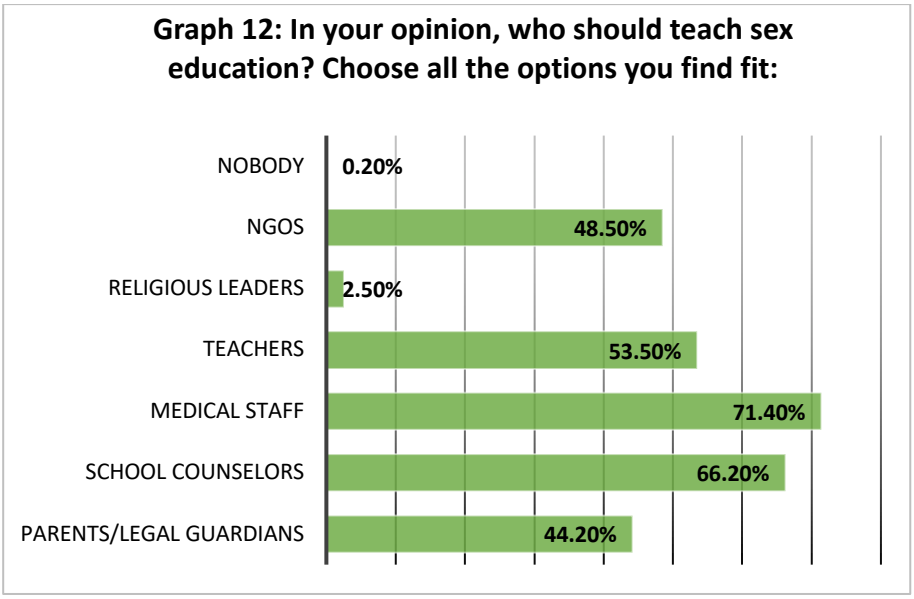
compulsory subject in schools."), which is analyzed in Graph 9. It emerged that respondents would be happy if the Ministry of Education were to introduce sex education as a compulsory subject in schools. Of the 518 respondents, 427 (82.4%) would like this subject to become compulsory. Surprisingly, this result contradicts that of the study conducted by Cult Market Research, in which 48% of respondents believe that sex education should be an optional subject and 46% that it should be compulsory (Neagu, A., 2022).



Graph 10 also shows a cross-tabulation between question no. 7 ("Do you have children?" YES/NO) and question no. 18 of the survey ("I would be happy if the Ministry of Education implemented sex education as a compulsory subject in schools."). This shows that the majority of respondents who state that they do not have children strongly agree with the introduction of sex education as a compulsory subject in schools, which corresponds to a percentage of 87%, i.e. 353 out of 406 respondents. The majority of respondents who confirm that they have children, 66% (74 out of 112), are also in favour of the introduction of this subject as a compulsory subject in schools.

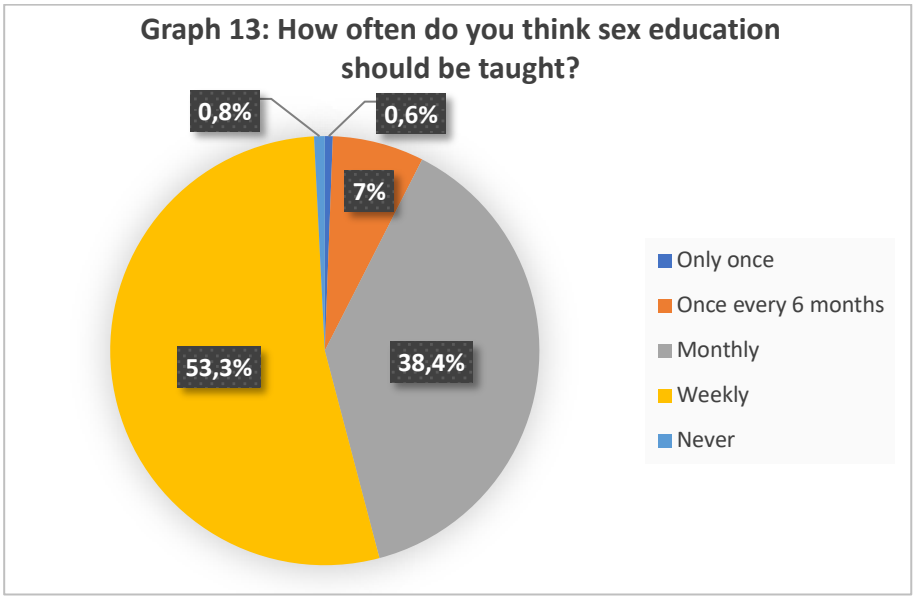


The statement "*The majority of respondents believe that sex education is necessary to prevent unwanted pregnancies, despite their religious beliefs*" was tested by analyzing the distribution by religious beliefs of the answers to question number 19 ("Sex education is absolutely necessary in schools to prevent unwanted pregnancies among young people"), analyzed through Graph 11. As can be seen, the majority of respondents believe that this matter is beneficial in preventing unwanted pregnancies.



"*The majority of respondents think that sex education should be taught by people trained in this field or by medical staff*" was another sentence we tested and it was confirmed (Graph 12). This result is consistent with the Cult Market Research statistic mentioned above, according to which more than half of the respondents think that this topic should be taught by people with training in this field or by people with a medical background (Neagu, A., 2022). Study participants were given the option to provide multiple responses, with medical personnel ranking first, followed by school counselors, teachers, and NGOs, while religious leaders accounted for only 2.5% of responses.

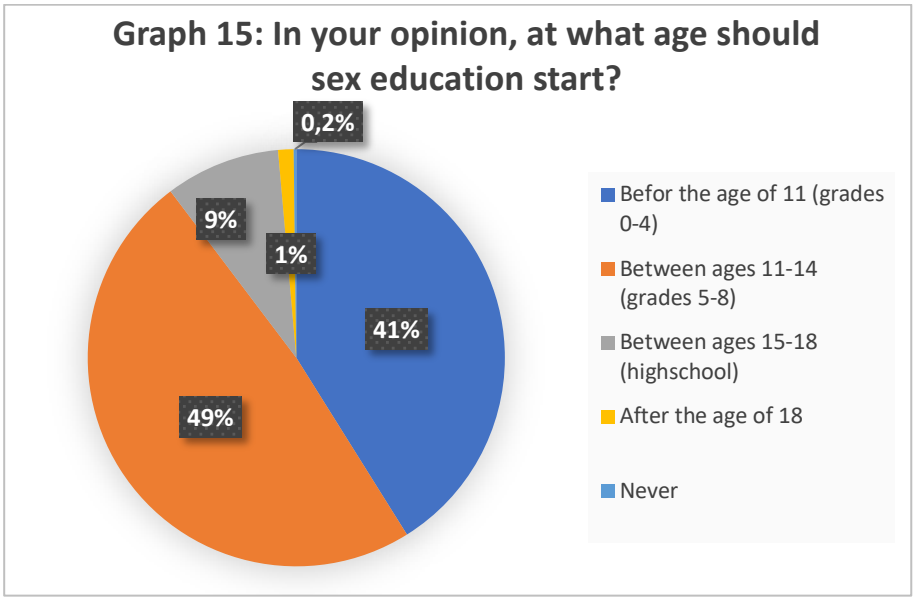
The data suggest that a collaborative approach involving medical personnel, school counselors, teachers, and nongovernmental organizations may be most effective in providing comprehensive sexuality education. The high value placed on medical personnel and school counselors underscores the importance of trained professionals providing accurate and sensitive information. While parents are trusted, their lower ranking suggests that they need resources and training to effectively engage in discussions about sex education at home. The low preference for religious leaders underscores the public preference for a secular and evidence-based curriculum, but the structure of our sample is heavily skewed (predominantly urban-educated respondents).



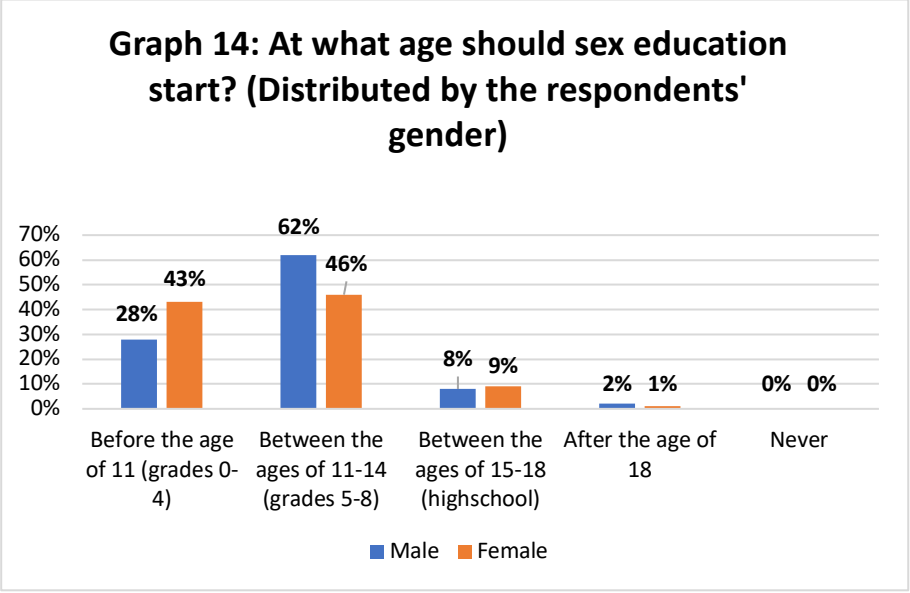
"*The majority of respondents are of the opinion that sex education should be taught weekly*" – this sentence is analyzed in chart 13. More than half of the respondents (53.3%) would like sex education to be taught weekly. This frequency indicates a strong preference for continuous and integrated learning, suggesting the need for a detailed curriculum that evolves over time, rather than a one-off or sporadic approach. A further 38.4% consider monthly lessons to be necessary, which still allows for structured learning and emphasizes

the importance of regular engagement with the subject. This result is also in line with the result of the study conducted by Cult Market Research with SECS, which found that more than half of the subjects believe that this subject should be taught weekly (Neagu, A., 2022). A small percentage are in favor of biannual lessons, indicating that they consider sex education as an additional subject rather than a core aspect of education. An almost negligible proportion of respondents believe that sex education should only be covered once or never. This underlines the strong consensus in favor of including the topic in education systems.

With the statement "*Compared to men, more women would like sex education to be introduced much earlier*", we wanted to test the extent to which women are more aware of the need for early sex education than men (the data in Graph 14). When analysing the overall sample (Graph 15), we can see that the largest proportion of respondents believe that sex education should start in grades 5-8 (ages 11-14). This coincides with the onset of puberty, a critical developmental period during which children experience physical and emotional changes, and it indicates a strong consensus that sex education should begin before high school but after early childhood. However, a very cohesive proportion (41%) also support the idea of introducing sex education in grades 0-4 (before age 11). This indicates a recognition of the importance of early sex education, which is likely to focus on basic topics such as body awareness, consent and boundaries taught in an age-appropriate way. Only a small percentage believe that sex education should begin in high school (9%) and very few respondents believe that sex education should begin after leaving school (1%). There is an almost unanimous consensus that sex education is necessary, with only 0.2% strongly opposing it.



The majority favor an early start to sex education (before or during 5th to 8th grade). This reflects the realization that early intervention can help children deal with physical and emotional changes more confidently. While early sex education (before age 11) is likely to focus on body awareness, safety and consent, sex education in grades 5-8 (ages 11-14) could address more advanced topics such as puberty, relationships and reproductive health. The lack of support for starting sex education at age 15+ indicates a belief that waiting too long could leave children unprepared for critical developmental stages.



In terms of gender analysis, our statement "Compared to men, more women want sex education to start much earlier" was correct. Women (43%) are more likely than men (28%) to favour starting sex education before the age of 11 (Figure 14). This discrepancy may reflect different views on early childhood education and the role of preventative awareness, with women possibly placing more emphasis on basic knowledge at a younger age. Males are more inclined to start education in adolescence (ages 11-14), which is consistent with the developmental stage at which they perceive the information to be more relevant. By and large, both genders agree on the need for sex education during school years, although the differences in timing reflect different priorities.

Discussions & Conclusions

The analysis of the collected data underlines the crucial importance of introducing structured sexuality education programs in Romanian public schools. Respondents are overwhelmingly in favor of comprehensive sex education covering various topics such as sexually transmitted diseases, consent, contraception, relationships, and sexual and reproductive health. This suggests that the benefits of sex education are widely recognized when it comes to equipping students with the knowledge they need to make informed decisions and avoid potential risks.

The majority of respondents are in favor of starting sex education between the ages of 11 and 14 (grades 5–8), although a significant proportion should start even earlier (grades 0–4). This reflects the general consensus that basic knowledge about health and sexuality should be taught before students reach adolescence, which is in line with international best practice. Notably, female respondents were more likely than male respondents to support earlier sex education, emphasizing that it is necessary for the safety and empowerment of young girls.

Among the topics most frequently identified as essential were sexually transmitted diseases, contraceptive methods, consent and the anatomy and functions of the human body. The emphasis on consent and STIs reflects the growing awareness of the need to address societal issues such as sexual violence and public health risks. Furthermore, the inclusion of relationships and mental wellbeing highlights the importance of a holistic approach to sex education that goes beyond biology.

Respondents strongly support having qualified professionals such as medical professionals (71.4%) and school counselors (66.2%) teach sex education. This underlines the need for educators who are well versed in the subject and able to handle sensitive topics with expertise and sensitivity. Parents and guardians were also recognized as important contributors, indicating the importance of collaboration between schools and families.

Weekly lessons were the most popular option for delivering sex education, chosen by more than half of respondents (53.3%). This suggests that the topic should be covered as a regular part of the curriculum rather than as an occasional or optional topic.

With this quantitative study, we wanted to test several key statements. The results confirm that the majority of respondents are in favor of introducing sex education in schools, regardless of political and religious opinions. Furthermore, despite their religious beliefs, most respondents believe that sex education is essential for the prevention of unwanted pregnancies. There is a strong consensus that it is important for trained professionals or medical staff to teach this topic and that weekly classes are preferred. In addition, a notable difference was found between the genders: Women were more often in favor of introducing sex education earlier than men.

Despite the strong support for sex education, some challenges remain. Religious and cultural attitudes continue to influence perceptions, with some respondents emphasizing the need to balance moral and ethical considerations. In addition, the lack of adequately

trained teachers and standardized curricula is a significant barrier to implementation. Concerns about potential misinformation, which were evident in respondents' experiences of NGO-led events, underline the importance of a scientifically based and unbiased approach.

Our research has obvious limitations. The results of the study are not fully representative of the entire Romanian population due to biases in the sample. For example, the respondents may include a disproportionate number of people with access to education or urban environments, which could distort the results. The reliance on self-reporting raises the possibility of social desirability bias, as respondents may have given answers that they consider more socially acceptable rather than reflecting their true opinions. This study provides a snapshot of opinions at a particular point in time, but does not capture changes in attitudes or behaviors over time. Longitudinal studies are needed to understand trends and long-term effects. The study may also not have adequately captured the perspectives of marginalized or underrepresented communities, such as ethnic minorities or people in rural areas, whose needs and opinions may differ.

In terms of recommendations, we can urge that the Romanian education system prioritize the introduction of mandatory sexual education programs tailored to the developmental stages of students and aligned with international standards for health education. It is necessary to develop a comprehensive training program for teachers, medical staff and school counselors to ensure accurate and sensitive delivery. In addition, schools should actively involve parents and guardians in the process by providing resources and workshops to align home and school education on sexual health issues. Last but not least, it is essential to conduct ongoing evaluation of sexuality education programs to measure their effectiveness and adapt them to changing societal needs.

While our study highlights important findings, its limitations must be recognized and considered in future research to ensure a more comprehensive and accurate understanding of the topic. The implementation of educational programs is an important step in promoting a healthier and better-informed generation.

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Original Article

Between ideals and reality. Critical reflections on basic training in Italian social work in the light of the results of research involving a group of municipal social workers

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Abstract
Is the Italian social work today capable of developing its own cultural and scientific knowledge? What conditions influence this internal production process within the professional community of social workers? These questions are the focus of a reflection conducted with a group of 70 social workers from the municipal social services. More than twenty years after the inclusion of social work within university education, the discussion on the ability of this discipline to produce original scientific knowledge is intense in Italian social work. Caught between an operation increasingly guided by bureaucratic models and an increasingly complex social reality, social work must find a way to produce knowledge through reflective processes that often find little space in the institutions in which social workers operate.

Keywords: Social work training; scientific knowledge; scientific production; reflexivity; institutional constraints; bureaucracy.

Foreword

Social work training is a highly complex and much discussed matter. This article intends to contribute to the debate on social work training by analysing the contents of some focus-

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group discussions involving approximately seventy social workers employed by the municipal social services in the Region of Friuli Venezia Giulia, in North East Italy.

The central issue addressed in this essay can be summed up as follows: is social work today capable of developing its own cultural and scientific knowledge? What conditions influence this internal production process within the professional community of social workers?

In order to answer these questions, the first section sums up the main problems facing basic training for social workers today. In greater detail, it highlights the complexity of pinpointing stable cultural training for a discipline that aims to intervene with tangible human needs, which are however socially and historically determined. The fact that social workers are called upon to intervene within an institutional system that shapes the conditions of their work makes the analysis plan even more complex, especially today, when municipal social services seem to be organised according to management models that do not advocate reflectiveness and the processing of individual scientific thinking.

The second section will analyse some of the focus groups' conclusions on the issue of basic training in social work. As you will see, social workers' reflections are very useful when it comes to showing just how complex it is for this professional community to follow up on the professional mandate of contributing to the development of critical knowledge by processing their working experience. Here we find one of the main issues that weigh on social work as a scientific discipline today, namely the fact that daily operations in municipality-run local social services are structured and evaluated according to bureaucratic canons. Opportunities for the scientific evaluation of their work is extremely limited, if not completely absent, as are the possibilities for taking advantage of professional supervision. All this seems to fuel an idea among social workers that "culture" and "scientificity" should be offered and discussed in other places, mainly within universities, while local services are increasingly perceived as the place "of practice". All this impoverishes the professional social work community's internal capacity to produce knowledge and to critically analyse the knowledge offered by university training centres.

Lastly, the third section will conclude with a reflection on the role played by university work placements in constructing the professional identity of future social workers. Work placements are an essential part of social work training, helping to shape professionals who should have the ability to combine theory and practice. If, however, the work placement takes place within an educational context dominated by a divide between theory and practice, in which the professional community in question primarily perceives itself as a working group that struggles to reflect critically and produce knowledge, then it would be necessary to start seriously reflecting on whether university work placements actually have the potential to help improve the quality of social work today.

Social work training: a structurally complex issue

Discussing the training of social workers is not an easy task, as this professional figure incorporates three very different social requirements (Dal Prà Ponticelli, 1987). On the one hand, social work has provided itself with a set of codes of conduct, both national and international, which outline the figure of a worker who should operate within a framework of values with a clear focus on social justice, inclusion, defence of the rights of minority groups, and welfare systems. On the other hand, social workers operate professionally through institutions that politically define the needs to be met, the beneficiaries of their

work and the results to be achieved through welfare operations. Lastly, social work takes place within social contexts characterised by specific political, cultural and economic conditions, which also influence the image and professional mandate of social workers.
The complex dynamic between professional mandate, institutional mandate and social mandate means that the identity and operations of national professional communities are structured in different ways, making it very difficult to identify the cultural and operational characteristics of social workers in a precise and unambiguous fashion (Hare, 2004). For example, social work in northern Europe, in Scandinavian countries, is characterised by an emphasis on sociological and political training content, in line with a universalist welfare structure, and social workers are familiarised with a professional role that looks at the social roots of the problems presented by users and the consequent factors of social injustice (Hutchinson and Kőrösy, 2007). On the contrary, in liberal welfare regimes, such as the USA and Canada, the university education of social workers is strongly influenced by medical and psychological disciplines, which focus more on exploring the origins of the problems presented by social service users within a micro-social dimension (ibid., p. 57). However, this does not resolve the intrinsic tension between universal and detail that has characterised social work since its historical origins. Indeed, it is certainly no coincidence that in the USA, the academic and professional community of social workers is characterised by heated opposition between those who advocate a political vision and critical approach to social work and those who, instead, continue to consider social work as a discipline predominantly oriented towards solving individual problems (Rossiter MSW, 1997; Turgeon, 2018).

These complex and diverse operational and training contents in social work are not only to be found in the comparison between different national situations, but also concern the historical development of this discipline that began life as a tool to solve the needs of the poorest social classes, but that, soon afterwards, realised that it was necessary to equip itself with conceptual apparatus able to strengthen social workers' interpretative and interventional skills (Neve, 2011). From its very beginnings, social work has sought to combine its mandate of attempting to solve the tangible problems expressed by a section of the population with the development of theories that could both explain the origin of these problems and guide professional action. Of course, it has never been possible for social work to come up with a definitive body of theory able to conclusively explain the genesis of problems that have historically appeared to be linked to the various conditions affecting human societies. The vision and mandate of social work and, as a consequence, its training content, have therefore changed over time, in connection both with progress in scientific disciplines of reference, and with changes in the institutional systems within which the social services have found themselves operating. In greater detail, the introduction of public welfare systems meant that social services were also required to act from a "political" perspective, becoming an executive instrument of a system that intended to extend social rights to social groups that had previously been excluded (Dal Prà Ponticelli, 1987).

As far as social worker training in Italy is concerned, we can say that it too has been affected by the historical, cultural, political and institutional conditions in which this figure came about and developed (Neve, 2011). In Italy, the inclusion of social worker training within academia was rather late, between the 1980s and 2000s, compared to the long history of professional social work in Italy. Previously, social workers were mainly trained by a set of regional bodies, which were either of a denominational stamp or associated with trade unions, whose mandate was to cover the working needs of local

social services within a welfare system that was fragmented into a plurality of interventions involving local authorities (regions, municipalities and provinces), the Church and the private social sector. All this has undoubtedly contributed to building the figure of the Italian social worker according to a predominantly welfare-based model, with actions centred on the response to individual problems, often through sectoral interventions and with limited resources to definitively resolve situations of need. This does not mean, however, that social work training in Italy has not historically presented the elements of internal contradiction that structurally characterise the heart of social work and are the product of the interaction between the three professional, social and institutional mandates, which are elements of tension that the professional community has tried to unite in conceptual terms. Indeed, since the late 1960s (Fargion, 2013), Italian social workers have developed their own original theoretical and professional intervention model, with an ecological-systemic matrix, which assigns this profession the task of simultaneously influencing the various social systems considered responsible for the generation, structuring and resolution of human problems: the individual; his or her social context of reference; the institutional system in which the social services operate. This "trifocal" perspective (ibid.) thus seeks to hold together the need to take care of the interpersonal relationship between social worker and user, developing a relationship oriented towards change and the resolution of human problems, while also not neglecting to work on the structural social components within which the same needs arise and are met. In greater detail, the professional community of social workers has always been very clear that the very definition of what a "need" is and how it should be addressed is the product of political processes that are embodied in laws, care regulations and professional job descriptions (Dal Prà Ponticelli, 1987). In the same way, the professional action of resolving needs has a "political" impact, since it legitimises the choices made with regard to the definition of needs and the objectives assigned to social interventions. We could say that, especially since the 1960s, social work has also seen itself as a factor of cultural reproduction in a social system that constantly produces economic and power inequalities and that, through the welfare system, tries to contain the emerging contradictions while not questioning the dominant configuration of social relations (cf. Dominelli, 2015; Heron, 2005). During the period of major reforms in the Italian welfare system, this political dimension's awareness of social work revealed radical criticism of social control exercised by welfare institutions, advocating the involvement of social workers in overcoming the asylum facilities operated by Basaglia (Foot, 2014), while also refusing to bring the basic social work training into the academic field (Samory, 1995). This had a negative effect on the scientific development of social work, weakening this discipline and the municipal welfare system as a whole.

With the subsequent inclusion of social work in university education, both in Italy and abroad, there has been a growing interest in learning more about the quality of training (Wilson and Campbell, 2012), but also concerns about the possible accentuation of the fragmentation of the theoretical content offered to students and the disconnection between theory and practice experienced during professional placements (Bressan et al., 2011). The fact that social work is the product of a synthesis of knowledge obtained from several scientific disciplines (sociological, psychological, anthropological, legal) and that it is translated into a practical activity, often disconnected from academia and research centres, makes the danger of widening the gap between theory and practice very real, while also running the risk of weakening the value and political dimension of social work.

All this, as Lorenz (2017) notes, is made even more complex by the structural characteristics of contemporary modernity in which the social services operate, a modernity in which the impoverishment of the sense of solidarity perceived in relation to those who live in situations of poverty, immigration and social exclusion is accompanied by a weakening of the collective protections guaranteed by public welfare systems. Picking up on Rosa's (2003) and Sennett's (1988) reflections on the corrosive nature of capitalism, Lorenz speaks of a "situationalist modernity" in which people perceive that they have lost control over their lives and cannot plan their futures with certainty, even in the medium term. Ours is a modernity in which even social work becomes "situationalist", since it too is required to remedy a small part of human problems without questioning the structural social factors linked to the emergence and evolution of these problems. According to Lorenz, this explains the importance that university social work education assigns to methodological teachings on intervention "technique", while less and less time is dedicated to reflections on the critical political role of social work. Certainly, not even the establishment of bureaucratic and corporatist management models for social services seems to be alien to this possible technicist and situationalist turnaround in social work, or the introduction of fixed-term contracts for social workers that makes medium- and long-term planning of interventions much more complex (Bertotti, 2016; Evans et al., 2012).

These reflections highlight how it is very difficult to draw a clear picture of what the characteristics of social worker training should be. Together with the need to accumulate technical and methodological knowledge in order to better address increasingly differentiated and complex human needs, the social worker also has to implement a professional mandate that is, essentially, the expression of both the democratic value system of liberal democracies, but also part of the cultural heritage of the European socialist tradition, with its calls for social justice and the defence of welfare systems (Lorenz, 2017). This libertarian and critical root was fuelled, starting in the 1960s, by youth protests, the feminist and homosexual movement and, more recently, by movements defending the rights of migrants and other ethnic minorities (Graham and Schiele, 2010; Rossiter, 2008; MacKinnon, 2009).

As we will shortly see by analysing the results of the research presented here, it seems that in the group of social workers interviewed, this ethical and political component, in addition to other aspects, has been sacrificed during their training and work due to pressure caused by a growing number of social problems in the population (such as the spread of poverty; the scarcity of services for the non-self-sufficient; the needs of the immigrant population, etc.). In fact, discussions with social workers also seem to reveal operations in which the methodological aspect, even if perceived as essential for good-quality interventions, is actually often neglected within organisations that force workers to carry out standardised bureaucratic work and in which the quality of the work is evaluated on the basis of business-type standards. Time for reflection, research, discussion and supervision seems rare, if not altogether absent. To summarise, we can say that the social conditions in which Italian social workers operate seem to intensify a divide between the three instances (professional, social and institutional) and that several problematic aspects emerge in this gap linked to the quality and structure of professional training for social workers in Italy.

Social workers' opinion on the training they received

The transition of social worker training from the old special schools to university courses was a moment of great change for social work, both in terms of theoretical content and teaching methods. Pre-university facilities could certainly not guarantee significant in-depth theoretical study and scientific research, and the teaching content was often based on developments from abroad, especially in the English-speaking world (Fargion, 2013, Neve, 2011). The introduction of social work into the academic world has paved the way for greater scientific depth, more focused on analysing the national situation, and for more multidisciplinary educational content. However, while something has certainly been gained in this transition, there is a feeling among social workers that something else has been lost. We will now look at four conclusions drawn by four focus groups on the topic of professional training in the social services, which involved approximately seventy social workers working in the municipalities of the Region of Friuli Venezia Giulia. As we shall see, these conclusions all coincide in highlighting how basic university training in Italy has improved the quantity and quality of the theoretical content offered to social work students but, at the same time, has increased the distance that has always existed in social work between theory and everyday operational needs.

"There is a clear gap between theoretical training and operational reality in social work. Perhaps this is also due to the interdisciplinary nature of our profession and the fact that our degree courses are taught by a plurality of lecturers from different scientific disciplines who often have no idea what a social worker is. There are some courses, including some master's degrees, which are very interesting from a theoretical point of view, with a philosophical or historical imprint, but far removed from the daily reality of social work. These courses offer unusable content. This may also be due to the fact that we have very few social worker lecturers teaching in universities, and this is probably also our responsibility, as we have clearly invested very little in research and teaching and this is the result." (group 1).

"Our educational experiences are very diverse and depend both on the universities involved, but also on the years of attendance and the different curricula. While the real strong point of the old-style basic training was the search for a connection between theory and practice, ever since this basic training has been included in university courses, which are far removed from professional practice, we have noticed a distancing of the theoretical content from the needs of operational practice. This is probably also due to the fact that many teachers who teach vocational subjects in university education have never had any practical practice." (group 2).

"Basic training has changed a lot and is very much devoted to the theoretical component and much less to the processing of practical experience. Entering university inevitably meant sacrificing something of the previous educational experience and we have to accept this, because we've done so much to get into university. There's much more emphasis today on student performance in exams. It is probably also a question of the interdisciplinary nature of the profession, with difficulties in giving a specific focus to social worker training. Furthermore, many university lecturers do not know what social workers do in social services, what their tasks are." (group 3).

"We have observed a disconnect between theory and practice, even with regard to vocational subjects. There is a lack of theoretical reflection on the relationship between social work and the political and institutional dimension. This discrepancy between policy guidelines and the real needs expressed by users is rarely addressed within university education." (group 4).

The first thing we can point out is that the four groups all agree in noting a gap between university training content and the operational requirements placed on municipal social workers, just as all four conclusions seem to see the university as the place where theory and practical operational needs should be combined. Of course, the amount of theoretical content offered in university courses, which is certainly greater than in the old special-purpose schools, seems to have further highlighted the difficulty of implementing a conceptual synthesis that could help to support social workers in their everyday practice. However, it must be stressed that the problematic nature of the relationship between theory and practice in social work has always existed, even before university education became available, not least because social work began life as a practical intervention and, subsequently and "slowly ... the idea matured that theoretical reference schemes were needed to guide practice" (Ponticelli, 1984, p. 19). This process of "mediation" (ibid., p. 22), which has been very slow in Italy, has been characterised by the extreme difficulty of trying to adapt theoretical contents – often developed in social and scientific environments that differ significantly from the Italian and European environment – to operational practices, in order to guide and/or justify the practice itself. Subsequently, over the last thirty years, an intense debate has developed in international social work about what it means to give a scientific framework to this discipline. The dynamic of this discussion is certainly very interesting as it is centred on a proposal for a constant relationship between practice and the exercise of reflectiveness, all within a methodological and theoretical framework of a scientific nature (see Fargion, 2013, pp. 23–46). In short, social workers today are expected to act reflectively, critically considering each stage of the methodological process implemented, making a connection with the content of theoretical disciplines and codes of ethics, and subjecting the results of their work to verification. In this way, the connection between theory and practice should not only be made in academia, but also – and we would say above all – by the practitioners who implement the interventions, e.g. in the social services themselves. To be more explicit, the idea that there is a theory tailored to practice in the field of social work seems to be the product of an outdated approach that is no longer suited to the needs and challenges of social work. The group of social workers does not seem to be particularly aware of all this, which can be partly explained if we consider some organisational variables that affect their work. Firstly, the almost total lack of time and opportunities to develop reflectiveness. In greater detail, almost none of the organisations of the 246 social workers interviewed in the FVG municipalities make any provision for professional supervision for social workers or research on the results of interventions. Secondly, almost all respondents stated that the bureaucratic workload, which takes up a large part of their professional time, has increased steadily. These two factors make it practically impossible to approach professional practice in a reflective way, taking time to explore the connection between theory and practice. Hence the perception that local service cannot be the place where one can/should test the contents received in theoretical training, even going so far as to process innovative contents. The divide between theory and practice is therefore confirmed as an aspect that has not been resolved at all, since it depends on institutional factors, social workers' lack

of opposition to the bureaucratic roles imposed on them and the revendication of a professional role that cannot be denied reflection, research and cultural comparison. This also has a negative impact on the ethical and political dimension of social work, as reported by a social worker participating in a focus group:

"… We are in constant danger of becoming completely absorbed in administrative work and we should rebel against this, not accept these kinds of expectations of us. If, however, the management expects you to do office work and sees compliance with bureaucratic procedures as the most important element, then you lose the potential for change at work ... and you reduce the available resources."

The feeling of losing the potential for change that should always be entailed in social work has much to do with the acceptance of an operational role subordinate to the demands of municipal administrators, governed by bureaucratic logic. As one focus group argued, when talking about the difficulty for social workers to implement interventions to promote community, it seems clear that often *"... Social work is seen as a sort of monitor to inform administrators about local issues, and also to reassure citizens, to reduce their anxiety, especially today when people are increasingly lonely, isolated, and in need of help. In short, we exercise a controlling role to the benefit of policy.*" (group 1).

Here we have confirmation that the compression of daily operations into an executive and performance model, evaluated according to bureaucratic logic, facilitates the loss of the ethical and methodological content of social work and the use of this profession for the purposes of political control. Some focus-group respondents were very aware of these dangers and verbalised their distress at seeing social work surrender to an executive role in political decisions, without the professional community attempting to develop its own vision of the reality in which it operates. Interestingly, it was mainly social workers trained in the 1970s and 1980s who were more critical and less willing to consider social work as a purely operational tool. Meanwhile, social workers who trained in the 2000s, on university courses and in a cultural climate very different to that of their older colleagues, were the main group to show less opposition to the executive and bureaucratic role they were called upon to play in their work. Here we perhaps have confirmation that the professional identity of the social worker has been redefined over the years and that this redefinition is also implemented through adherence to the role proposed by the welfare institutions.

All this brings us to analyse another important training tool provided during the university education period: work placements for social work students. We will discuss placements because it is also through them that students are familiarised with the role of a social worker and because university work placements should be an example of how to bridge the gap between the theoretical and practical dimensions. However, as we will see shortly, the available data do not seem to indicate that the training experience offered by work placements is better able to teach future social workers how to combine theory and practice. On the contrary, it would seem that work placements also contribute to fuelling the idea that "theory is one thing, practice is another" and that, above all, this "practice" could confirm not only a tendentially executive, operative image of the social worker, but also a scarcely change-oriented, substantially conservative vision of this profession.

Work placements in the university education of social workers: a wasted opportunity?

Even after the inclusion of social work in academic training, work placements have continued to be recognised as an integral part of building the professional identity of future social workers.[1] The aim of work placements is to allow students to experience practical activity and associate it with the theoretical dimension, fostering the development of an initial professional identity (Studi Zancan, 2002). Through work placements, students are therefore familiarised with a professional role that should be centred on the ability to keep the theoretical contents together with the operational needs related to the three professional, social and institutional mandates, in both a critical and dynamic fashion. This process of learning in the field should therefore enable the cultural reproduction of a professional community capable of analysing and acting critically with regard to both its theoretical and practical dimensions. Once again, therefore, we see an emphasis on the fact that it is in the operational phase that the natural gap between theory and practice, which structurally characterises social work, should be bridged. It is considered a discipline that arises from practical instances outside academia, but which needs to construct its own theoretical conceptual framework both to provide a basis for its actions and to legitimise itself socially.

The problem, however, is that the data obtained from our research does not seem to suggest that work placements alone can play this role of building a professional identity capable of combining theory and practice. This seems to be due to a set of variables linked both to academia and to the organisational characteristics and methodological approach of municipal social work.

With regard to academic variables, the interviewees highlighted how university education is often characterised by a logic of accumulating credits in a short period of time, as well as mentioning how social work students often perceive work placements to be like any other training activity, as reported in the conclusion reached by one focus group:

"The aim of the work placement student is often to complete the university course by doing a work placement, with the placement beings increasingly similar to any other study subject for which a final grade is awarded. Students' attention is often more focused on the completion of their education, making no real distinction between theoretical examinations of any kind and the work placement." (group 1).

Two other focus groups also pointed out the same problem, highlighting how this logic of accumulating university credits in a short timeframe makes it very difficult for social workers' supervisors to find sufficient time for encouraging adequate reflection on the relationship between theory and practice, and on the problems that can emerge during practical work.

[1]Work placements for university students studying social work is a compulsory activity, as established by Presidential Decree 509/1999 and Ministry of Education, Universities and Research Decree 270/2004.

"We had a very rigid structure, including as regards work placements, with clearly defined time periods, which were decided in close continuity with the course on social work methods and techniques, so as to ensure a connection between theory and practice. Today we see placements being completed during the summer or even the year after the methods and techniques course, completely unrelated to the professional theory part. All too often, the questions that arise during practice cannot be studied in the theory part." (group 2).

"With university education, it is often the case that supervision is required for work placement students who have to complete their placement in a very short time, sometimes just a couple of months. This is due to a combination of factors within the university and what we then have to deal with is an intensive placement, compressed into too short a time frame to be useful and educational. There is no opportunity to reflect on their practice and make connections with theory, taking the time to discuss this with students. Done in this way, a work placement is of no use other than to complete the course of study." (group 3).

Another focus group highlights the difficulty of structuring an effective educational relationship between universities and social services and how this results in a deterioration in the quality of the education and training offered to social work students:

"In the old style of training there was more opportunity to understand what the motivations were in choosing to be a social worker and this was then discussed between the teaching staff at schools and the work placement supervisors. Nowadays all this is much more difficult to do, everything is done much more quickly and even university tutors, who are the supervisors' contacts for work placements, tell us that, in the event of problems, it is not easy to deal with difficulties such as these at university. In the old system, when we had end-of-year discussions with teachers of vocational subjects about work placements, they actually investigated why we wanted to continue with our studies and this has been worked on less and less over time. It now feels like doing chemistry, engineering or social work is all the same." (group 4).

Widening the analysis horizon, according to some of those interviewed, the different cultural context in which social workers are trained nowadays also plays a part in making it more difficult for work placements to shape a professional identity in which ethical and political aspects of the profession are valued, as we can read in the conclusion reached by this group:

"The final year of the work placement, done in stages, over time, had a specific educational significance. We had the opportunity to take responsibility, to put ourselves on the line, and to clarify our motivations for being a social worker. Perhaps we had more ideal and political motivations than today's young people, who have a wider range of choices. ..." (group 5).

The respondents show a very clear understanding of some of the management problems associated with the transition from basic training provided at the old special-purpose schools to universities, and the effects of this on the training of future social workers. However, what did not emerge in the group discussions was a critical reflection on the image that a municipal social work placement conveys to students. While, as we saw in the previous section, there is a fairly widely shared idea that routine and standardised operations are increasingly prevalent in basic social work, stripping social workers' job of its professional contents, in the group discussions no considerations whatsoever emerged regarding the fact that work placements, carried out in such an environment, could accustom students to the mainly bureaucratic role of the profession. The fact that the reflective dimension is significantly lacking in the daily work of social workers could confirm an idea among students that "theory is one thing, practice is another", thus accentuating the distance between the theoretical dimension and professional operations. And perhaps it is precisely because of all this that the social workers in the focus groups attributed universities with the role of trainer, even as regards those purely professional aspects that should be learned above all during the work placement experience, as we can observe in the following discussion passages:

"We find university education only partially adequate, very theoretical and generic, and disconnected from professional reality. For example, there is very little training on the organisation of social and health services and levels of responsibility. Training would also be needed on how to produce written documentation in social work and how to communicate in writing."(group 1).

"University courses in social work lack training in administrative procedures, in the administrative process to be followed by social workers in a municipal administration. In addition, we notice the students have a lack of training in communication with users." (group 2).

"More selection should be made with regard to people applying to work in social services. Not everyone is suited to this job and certain personal qualities are also needed to be able to do it well. Universities do not perform this role of selecting students." (group 3).

How to produce professional written documentation, how to relate to users and how to evaluate the professional qualities of future social workers are aspects that should be central during the professional training experience. They can primarily be evaluated during practical experience and much less so during theoretical training. However, the problem is that social work lacks a model for analysing and supervising the daily work of social workers, who are not used to reflecting critically on their personal and professional dimensions. In the absence of a reflectiveness that balances out practical work, it is easy for even the basic training to be deprived of its potential to create professionals able to interpret their own actions critically, to contribute to questioning theoretical content and to fuel the debate on the role played by social service institutions, thus replicating over time a professional model based increasingly on the mere execution of tasks, often assigned to social workers by the administrative structure. As Dominelli (2015) argues so well, social

work without the reflective dimension, without critical debate and the political component can easily be reduced to an instrument of further oppression for those who experience conditions of need that are also determined by structural social factors. The familiarisation of social work students, through work placements, with a role devoid of reflectiveness could accentuate the dangers of reproducing a professional habitus that transforms the social worker from an agent of change into an instrument for preserving dominant configurations of power.

Conclusions

The contents of discussions among focus groups made up of municipal social workers open up numerous critical reflections on the quality of basic training in social work. One difficulty that has always been present in this theoretical and practical discipline is the fact that it is complex to keep instances together that are sometimes very divergent. As we have seen, the professional mandate outlines social work as a profession strongly anchored in the ideals of democratic societies and assigns this profession the role of guarantor and promoter of the rights of the economically and politically weaker sections of society. On the other hand, social and institutional bodies sometimes ask the social services to act in a way that does not always comply with social work codes of conduct. These divides and conflicts between different expectations (of promotion and protection of rights/control and limitation of access to welfare resources) are made even more evident today by the accentuation of corporate models of governance in municipal social services, which shape the bureaucracy involved in social workers' jobs. The request that seems to come from the social workers interviewed is for a basic training that can heal this growing divide between the theoretical dimension and practical professional experience. This question, however, seems to arise from the assumption that it is only at university and during training that future social workers can be given the tools to deal with an operational reality that is judged to be far removed from what is taught in university lecture halls. What seems to emerge from the social workers' discussions is the idea that there is no room for producing knowledge during operations themselves, confirming a vision of professional action that is lacking in reflectiveness and proactivity. Within this framework of analysis, the training role played by work placements should also be reconsidered. In a context in which social workers express an essentially executive and bureaucratic vision of their professional mandate and in which there is a lack of time for reflection, delegating the construction of the professional identity of future social workers to professional training appears to be an operation that will not help social work to strengthen itself culturally and will not support the revival of local social services. On the other hand, social work training certainly needs an academia that does not accentuate the fragmentation of the theoretical content offered to students, but also a professional community that claims the possibility of having time and tools for reflection, through research, supervision and continuous training. Universities and professional associations of social workers should create an educational relationship centred on the enhancement of these capacities for the cultural and operational growth of social work. On the one hand, universities should direct basic training more towards exploring the issues most important to social workers, as well as providing future social workers with the tools they need to do research, supervision and produce professional knowledge. On the other hand, the community of social workers should claim more time for reflectiveness, offering new models of intervention to administrators and being more active on a social and political level. The academic community and the social services

community should perceive themselves as two poles of the same professional community whose quality depends on mutual interaction. The current social climate calls for social work equipped to read the situation and intervene in processes of exclusion and violence against human groups that are in a state of great economic and political weakness. We do not need social workers who act as "executors" and "bureaucrats", but instead we need complex professionals.

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Original Article

Associations: Mirrors for people living with Parkinson's disease

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Abstract
Parkinson's disease, with its profound impact on individuals and communities worldwide, calls for a comprehensive understanding of the social dimensions of the illness. This study explores the pivotal role of associations in influencing coping strategies and shaping identity among individuals living with Parkinson's disease. Through a grounded theory approach, the research examines how participation in associative networks provides a platform for self-expression, mutual support, and engagement, fostering resilience and adaptation. Data were collected via semi-structured interviews with individuals diagnosed with Parkinson's and facilitators actively involved in Italian Parkinson's associations from northern, central, and southern regions of the country. The findings underscore the critical role associations play in addressing the collective needs and aspirations of their members while highlighting significant regional differences in activities, strategies, and support systems. Associations promote solidarity and shared understanding through homophily, offering a sense of belonging and mutual aid. They not only provide access to essential social and healthcare resources but also create spaces where individuals can reflect on their past, navigate the present, and envision a future beyond the limitations of their condition. This dynamic interplay of social engagement and identity transformation underscores the indispensable contribution of associations to the broader care ecosystem and their transformative impact on the lives of people with Parkinson's.

Keywords: social identity; disease management; patient support services; community networks; social interaction.

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Introduction: associations as catalysts for civic engagement and healthcare evolution

Associations, defined as organized collectives pursuing shared goals, emerge as key products of modernization, creating autonomous spaces independent of state and market powers. They act as tools for transcending status inequalities, facilitating new forms of social interaction, and serving as collective agents that, through political participation, empower individuals in conditions of weakness or subordination.

The role of associations is a well-established sociological concept, as Tocqueville's observation (1835-1840), still relevant today, highlights how associationalism represents a liberty of action and a cultural model in which participation is regarded as both a right and a duty of every citizen. This model reinforces values such as liberty, equality, and solidarity, contrasting with the European context, where associations often require state protection to function. In this sense, associations in the present study are considered as collectives formed either through voluntary individual decisions or from top-down initiatives, based on shared or complementary interests that can develop institutionalized forms. Gallino (1978), for instance, defines an association as a stable collective oriented toward achieving common goals unattainable by individuals alone, whether created voluntarily or established from above, with an organizational structure promoting solidarity and cooperation.

This research specifically regards associations as a model of civic participation essential for societal development, adopting an individualistic approach. In this context, the shared interest is identified in the patient role, which seeks solutions to health-related challenges. These needs, viewed as purpose-driven rational actions, drive intentional aggregation and institutionalization of nonprofit groups designed to engage politically with the welfare state.

From the 1970s and 1980s onward, there has been a growing trend of citizen participation in the healthcare sector, expressed politically through the institutionalization and involvement in associations (Maturo 2024). Through these forms of participation, patients, caregivers, and professionals become central actors in the planning, organization, and management of healthcare services. As noted by Graffigna and Barello (2016), this managerial involvement reflects the need for social consensus to implement appropriate and effective policy measures informed by the perspectives of those living with the illness daily.

The partnership between associations and healthcare organizations, in light of the increase in chronic conditions and life expectancy, gives rise to decision-making processes capable of addressing economic and bureaucratic difficulties that hinder access to healthcare. In a healthcare system often characterized by bureaucratic rigidity and technocratic approaches, associations create relational assets that overcome institutional barriers. Associations value citizens as users, patients, and caregivers, allowing for the emergence of needs and preferences that would otherwise remain ignored by managers, healthcare professionals, and policymakers (Giarelli, Lombi and Cervia 2020). Associations do not merely fill the gaps left by the welfare state but redefine public space, contributing to a new civil society characterized by pluralism of social subjectivities (Giarelli, Lombi and Cervia, 2020). At the macro-social level, they actively participate in defining health policy priorities, setting shared goals, and outlining intervention strategies. Therefore, associations serve as a bridge between state institutions and individuals,

activating forms of solidarity and promoting social rights to health. Voluntarism is the guiding principle of civil society, and associations are its main collective actors, where commitment and shared responsibility are prerequisites for participation (Dekker and Broek 1998). In modern society, individualism does not hinder volunteering; the reasons for involvement are personal choices, often driven by the need to address individual health needs. The desire to acquire skills and meet personal needs encourages decisions ideally made through debate and exchange of arguments, avoiding hierarchical or economic impositions. Through these dynamics, associations produce private assets for members, solidarity assets such as mutual support, and public assets such as the creation of shared spaces (Dekker and Broek 1998). In fact, these needs emerge primarily where the welfare state does not guarantee the enjoyment of social or health rights, especially for the most vulnerable groups. Associations avoid asymmetrical power relations and foster inclusive decision-making processes, integrating direct experiences and subjective specificities. In this context, they represent an intermediate space between the state and membership groups, acting as intermediaries between formal and informal needs, contributing to social cohesion and improving health (Maturo 2024).

Although it is clear that, from a macro perspective, associations play an instrumental role in strengthening the healthcare system and democratic participation, promoting trust and cooperation within the social fabric, the micro perspective offers a complementary view. The latter focuses on how associations respond to the particular needs of individuals. In meeting these specific needs, associations also perform general functions, such as the creation of social networks and the strengthening of a sense of belonging. In light of this, the following research adopts the interpretive framework of Georg Simmel's formal sociology (1908), which views society as a form of association composed of a network of interconnected social circles. From this perspective, the individual simultaneously participates in various associations that intertwine multiple and sometimes contradictory interests. This complex system creates a unique network of affiliations for each individual, making it unlikely that two people share exactly the same combination of relationships.

Our analysis focuses on the interests and individual motivations that contribute to the formation of associations, considering the differences that emerge between collective representations and personal reasons. These differences find an analogy in the reciprocal relationship between individuals, a central element for understanding the functioning of associations, particularly in the context of illness. This approach highlights how associative dynamics are the result of the complex interaction between individual singularities and structural constraint.

Associations as agents to overcome stigma in Parkinson's Disease

From a sociological perspective, associations for people with Parkinson's disease serve as generators of social capital, understood as the resources derived from networks of relationships and mutual trust. These connections - both horizontal among patients and caregivers and vertical with healthcare professionals and political institutions - provide critical support in addressing the challenges posed by the disease. The activities organized by associations contribute to building networks of emotional and practical support, alleviating individual isolation, and strengthening the sense of community belonging. Moreover, social participation in the healthcare sector, involving patients, caregivers, professionals, and other actors, positions associations as key players in scientific dissemination, research promotion, power-sharing, and defining ethical priorities. These activities make associations crucial advocates in governance dynamics and health-related

decision-making processes. Social capital generated by associations, analyzed from a micro perspective focusing on the individual, aligns with a model that views social networks as essential resources for individuals living with illnesses (Maturo 2024).

In this context, the wealth of relationships fostered by associations highlights central nodes for constructing support networks, which promote emancipation from the disease, increase public knowledge, and create self-help groups. Associations specifically aim to support individuals affected by conditions that interfere with fulfilling social roles and often lead to a progressive withdrawal from public life by those affected and their families (Geerlings et al. 2023).For instance, "Shaking Palsy" or "Paralysis Agitans", first described in 1817 by British physician James Parkinson (Parkinson 2002), reveals a social dimension of sickness whenever the afflicted individual is labeled as unwell in the social sphere (Twaddle 1979). The disease manifests not only as a biological condition but also through interactions and experiences that are inherently social, as the individual continually relates to their social environment (Bury 2005).

Motor symptoms such as dyskinesia, tremors, rigidity, bradykinesia, postural instability, and walking difficulties (Parkinson 2002; Chaudhuri et al. 2011), alongside non-motor symptoms like anosmia, visual disturbances, pain, paresthesia, orthostatic hypotension, depression, anxiety, cognitive decline, sleep disturbances, constipation, and dysphagia, significantly contribute to social isolation. These symptoms not only worsen emotional well-being but also trigger a vicious cycle: depression, reduced social activities, fear of falling, and anxiety feed into one another, further reinforcing social withdrawal behaviors (Ahn, Springer and Gibson 2022). Additionally, language difficulties, fears of making communication errors, anxiety, and depression are among the most frequently associated factors with social withdrawal. Finally, cognitive decline and the increased risk of dementia exacerbate this situation, making isolation even more pronounced (Ahn, Springer and Gibson 2022).

The voluntary and involuntary social withdrawal of people with Parkinson's disease and their family members often stems from the fact that the typical symptoms of Parkinson's disease hinder adherence to shared social norms, leading them to feel shame (Nijhof 1995) and withdraw into private spheres. The symptomatic fluctuations typical of the disease make it difficult to follow social rules. However, shame is not only a consequence of "deviant" behavior but also depends on the social significance of the broken norms, the visibility of these behaviors, and their public labeling as deviance (Nijhof 1995). This dynamic inevitably leads to a confrontation with the issue of stigma (Goffman 1963), which amplifies social isolation and psychological distress.

What is medically attributed to cellular degeneration in the nervous system that leads to chronic motor control and balance disturbances (Poewe et al. 2017) translates, for people with Parkinson's, into an experience often described as an "atomic bomb" that throws everything into chaos, a metaphor used by individuals with Parkinson's to highlight a profound loss of autonomy and an increased sense of stigmatization (Florijn et al. 2023). The narrative review conducted by Prenger et al. (2020) broadens the understanding of the disease, emphasizing that, in addition to motor and cognitive symptoms, social symptoms impact quality of life in even more significant ways. The authors identify several factors that hinder social interaction and communication, including the bradykinesia of facial muscles, which causes a masking of facial expressions, described as one of the most impactful emotional symptoms for people with Parkinson's (Prenger et al. 2020). Maffoni et al. (2017) highlight how stigma emerges from an exchange of perceptions: patients with

Parkinson's often complain of being misunderstood by others, while at the same time, they perceive the discomfort of those interacting with their physical problems. These misunderstandings arise from interactions that fail to meet social expectations and often lead to withdrawal from the social context (Maffoni et al. 2017). This dynamic makes it urgent to find solutions to prevent stigma from being experienced as an additional "non-motor symptom of Parkinson's disease" (Maffoni et al. 2017: 6).

In light of this, the active participation of people with Parkinson's and their family members in associations is crucial for reducing isolation and social withdrawal. Associations play a fundamental role in public awareness, directly addressing the social stigma associated with the disease. According to Ahn, Springer and Gibson (2022), social activity programs have shown positive effects in maintaining and improving social participation. In fact, these associations, acting as bridges between the healthcare system, families, and the community, represent a transformative force. They combine solidarity, empowerment, and social progress to overcome stigma and prevent social withdrawal. As stated in the Parkinson's Manifesto for Europe (Parkinson's Europe 2022), "Make it easier for people affected by Parkinson's to connect with others in the Parkinson's community to share experiences and knowledge, thereby addressing isolation and providing motivation and inspiration". Associations created for individuals with Parkinson's and their caregivers play a crucial role by providing resources and fostering social connections. During the COVID-19 pandemic, these associations became even more indispensable, addressing the heightened isolation and disruption of care routines experienced by people with Parkinson's. Lombi (2022a) highlights that individuals with established coping strategies often relied on these associations for assistance, further cementing their role as essential support networks.

Improving the quality of life for people with Parkinson's disease (PD) requires coordinated actions by associations in collaboration with the healthcare system. These efforts include organized activities, support services, and the promotion of innovative solutions. Collectively, these initiatives contribute to the process of preserving the self despite, the sickness label, enabling individuals to navigate daily challenges related to their roles and identities within social and personal contexts. In particular, associations support preserving self-strategies, which help individuals with PD maintain their sense of identity through "interacting" and "taking action" (Vann-Ward, Morse and Charmaz 2017). As noted by Vann Ward, Morse and Charmaz (2017) using a constructivist grounded theory approach, preserving self in the context of PD involves two interrelated processes: interacting refers to how individuals redefine their sense of self through relationships with others, transforming their identity via social engagement; while taking action involves constructing a self-identity in relation to others, rooted in the perception of who they were before the diagnosis and who they aspire to be after it. The symptoms of PD often force individuals to confront the inability to perform activities they once considered integral to their identity; therefore, this necessitates a redefinition of self, reconciling their past sense of self with their current capabilities in activities that they now consider fundamental (Vann-Ward, Morse and Charmaz 2017). Through new interactions and adaptive actions, individuals create reimagined identities, allowing them to navigate life with Parkinson's in a meaningful way.

This identity reframing enacted by people with Parkinson's can be interpreted as a challenge to "sickness imagery" (Maturo 2007), both on an individual and institutional level. This capacity for reinterpretation and renegotiation of identity is particularly evident in the work of associations. As noted by Lombi (2022b), associations, as the core of

networks of cooperative relationships, address the social aspects of the disease, promoting actions aimed at changing the perception of Parkinson's. Among the primary initiatives are the fight against stigma and support for the recognition of the rights of people with Parkinson's. Through these actions, associations play a crucial role in fostering an alternative and more positive narrative of the condition, helping to create a bridge between the private and public dimensions of the disease.

Research design

Reason and aim of the research

In light of the considerations raised, including the complexity of symptom fluctuations in Parkinson's disease, the difficulties stemming from stigma, and the crucial role of associations in improving quality of life, a key research question emerged: *How does active participation within associations contribute to the intricate process of identity formation among people living with Parkinson's disease?*

This question emerged unexpectedly during the author's doctoral research period, where the significance of associations as mediators between the private experience of the disease and the public experience became apparent, as well as their role as key actors in supporting individuals in the complex process of identity construction and renegotiation. Therefore, the aim of this research is to explore how active involvement in associations contributes to shaping the identities of individuals living with Parkinson's disease. This identity reframing enacted by people with Parkinson's can be interpreted as a challenge to "sickness imagery" (Maturo 2007), both on an individual and institutional level. This capacity for reinterpretation and renegotiation of identity is particularly evident in the work of associations. As noted by Lombi (2022b), associations, as the core of networks of cooperative relationships, address the social aspects of the disease, promoting actions aimed at changing the perception of Parkinson's. Among the primary initiatives are the fight against stigma and support for the recognition of the rights of people with Parkinson's. Through these actions, associations play a crucial role in fostering an alternative and more positive narrative of the condition, helping to create a bridge between the private and public dimensions of the disease.

Methodology

This research uses semi-structured interviews and adopts a qualitative methodological approach based on Grounded Theory (Glaser and Strauss 1967). This methodology allows for an in-depth exploration of active participation processes and their impact on the identity of individuals with Parkinson's disease, providing a thorough understanding of the social and individual dynamics that emerge within associations.

Data collection

Between February and May 2023, semi-structured interviews were conducted by a single researcher. The interviews took place at the offices of associations dedicated to people with Parkinson's disease and their families. The associations played a key role in recruiting participants, disseminating the research objectives, and ensuring anonymity. Through theoretical sampling, the saturation of key categories was ensured, with strategically selected associations reflecting regional diversity across Italy. Seven associations were

involved two based in the Piedmont region, and one each in Lombardy, Tuscany, Lazio, Puglia, and Sicily[1].

Sampling

The self-selected sample involved a total of 74 people who gave their consent to participate in the study, but the actual number of interviews conducted were 59. Of these, 44 were individual interviews with people with Parkinson's disease, while 15 involved both the person with Parkinson's and informal caregivers. The caregivers, who played the role of "facilitators" (Low 2012), were crucial in shaping the narrative during interviews, particularly in cases involving individuals in the advanced stages of the disease. As shown in Table 1 a total of 59 people with Parkinson's (36 men and 23 women). As shown in Table 1, a total of 59 participants with Parkinson's disease (36 men and 23 women) were included in the study, distributed across the Italian regions where the involved associations are based. The average age of participants with Parkinson's disease is 67,7 years, with a standard deviation of 10,5 years. Specifically, the average age for male participants with Parkinson's disease is 66,9 years, while for female participants with Parkinson's disease, it is 69.0 years.

Additionally, 15 informal caregivers participated in the interviews, distributed across the regions where the associations operate (Table 2). Their average age is 65 years, with a standard deviation of 11,5 years. The caregiver participants consist of three male participants, with an average age of 72,3 years, and twelve female participants, with an average age of 632 years.

Table 1. Participants with Parkinson's disease included in the study

Region	PwP (F)	PwP (M)	Total PwP
Piemonte	6	12	18
Lombardia	6	5	11
Toscana	2	7	9
Lazio	2	2	4
Puglia	4	3	7
Sicilia	3	7	10
Total	23	36	59

[1] The following seven Parkinson's associations are gratefully acknowledged for their support: Associazione Amici Parkinsoniani Piemonte, Associazione Parkinson Arezzo: A.P.AR, Associazione Parkinson Insubria sezione Groane Onlus, Associazione Parkinson Puglia OdV, Azione Parkinson Ciociaria, La Parkimaca - Ass. Parkinson Cuneo e le sue valli, and Libera Associazione Parkinsoniani.

Table 2. Informal caregivers participating in interviews with relatives who have Parkinson's disease

Region	Caregivers (F)	Caregivers (M)	Total Caregivers
Piemonte	6	0	6
Lombardia	3	3	6
Toscana	2	0	2
Lazio	0	0	0
Puglia	1	0	1
Sicilia	0	0	0
Total	12	3	15

Data analysis

During the data collection period, the audio recordings of the interviews were transcribed and analyzed comparatively using NVivo software. Identifiable information was removed from the transcripts to ensure anonymity.

The coding process was daily guided by the concept-indicator model (Strauss 1987). Through the interviews and observations, the fundamental elements of Grounded Theory, as defined by Strauss (1987), were identified as empirical indicators.

Specifically, the three concepts identified through conceptual coding were: *Associations' activities*, *Coping strategies adopted by association members*, and *Identity expressions*. These three concepts were developed through the identification of empirical indicators, which were then compared with each other in terms of differences, similarities, and degrees of coherence. This comparison allowed for the refinement of the categories until conceptual saturation was reached.

The conceptual specification of *Associations' Activities* was defined through various indicators such as: motor activities, recreational activities, individual activities, group activities, face-to-face activities, remote activities, types of professionals involved in activities, number of sessions per activity, location of activities, equipment used in activities, use of digital resources, publicity of activities, costs of activities, frequency of activities, participation in activities, average duration of activities, feedback on activities, and accessibility of activity locations.

The concept of *Coping Strategies Adopted by Association Members* was considered saturated through indicators such as: accounts of problems and how they were addressed, experiences of stigma, physical difficulties encountered, requested assistance, the role of caregivers in supporting daily life, frequency of sharing personal experiences, use of techniques to cope with symptoms, use of medications to address symptoms, use of resources, adoption of unconventional strategies to face daily challenges, participation in activities to develop new skills, participation of caregivers in activities aimed at defining coping strategies.

Finally, the saturation of the concept *Identity Expressions* was reached through indicators such as: use of metaphors, images, and photographs, linguistic choices, modes of presenting oneself during the interview, presence or absence of companions, narratives of the moment of diagnosis, difficulties experienced during the interview, statements about future perspectives, and willingness to participate in the association.

The process of conceptual coding represented the first step in identifying the core categories (Strauss 1987) and their related subcategories. During the analysis, it was deemed appropriate to adopt the same names of the concepts as core categories. This result did not stem from a guided approach, but from the fact that the concepts emerged spontaneously during the research, initially conducted for other purposes, fully adhering to the principles of Grounded Theory.

Results

The following table (Table 3) presents the main categories and their related subcategories to be explained

Table 3. Categories and subcategories

Associations' activities	**Territorial approaches to rehabilitation**
	Progressive adaptability of activities
	Compensatory activities
Coping strategies adopted by association members	Medical provider selection
	Preparatory practices
	Dealing with stigma
Identity expressions	Parkinson as an unwelcome guest
	Parkinson's is a cohabitant
	Parkinson's as a dominant identity

Associations' Activities

From the words of the interviewees, a variety of activities within the associations emerged, ranging from medical interventions to recreational initiatives. Medical activities include rehabilitation sessions, medical visits, and speech therapy. In parallel, recreational activities are organized that not only provide entertainment but are also functional in managing Parkinson's symptoms. Among these, dancing, particularly tango therapy, and practices such as Tai Chi, which promote movement and physical well-being, stand out. Recreational activities, such as organized trips and online meetings for discussions and leisure, complete the offerings. More specific initiatives include the use of psychologists, self-help meetings, and promotional activities. The latter may involve the use of applications or tools useful for participants, highlighting the commitment of associations in supporting members through innovative resources.

Territorial approaches to rehabilitation

It emerged that all the associations share the commitment to organizing rehabilitative activities; however, these activities vary significantly from region to region, reflecting geographic, cultural, and logistical factors. For example, Nordic walking is particularly popular in mountainous regions like Piedmont, where the terrain lends itself to this practice. Conversely, swimming is more widespread in coastal areas such as Sicily, where the availability of aquatic facilities facilitates access to such activities.

These differences highlight the adaptability of associations in shaping their offerings based on regional contexts. In areas where territorial compliance is a challenge, rehabilitative activities are often carried out within association premises, adapted with the aid of specific tools. During the COVID-19 pandemic, many of these activities were transferred online, ensuring continuity even under extraordinary conditions.
As one interviewee stated:

In the sense of sailing, canoeing, all sporting activities for young Parkinsonians. (P_23_M_64)[2]

It has been a very nice experience with the young people, especially because even today, once a week, I continue to do Nordic walking with them. I am still part of a great group (P_36_F_64)

Progressive adaptability of activities

The activities proposed by the associations reveal their ability to progressively adapt to the different stages of Parkinson's disease. The diagnostic criteria of the International Parkinson and Movement Disorders Society (MDS) divide the disease into three main stages: prodromic, early, and advanced (Artusi and Lopiano 2022). The prodromic phase, characterized by the onset of early motor and non-motor symptoms until diagnosis, is generally not associated with participation in associations. In this phase, the disease is perceived as a concerning but still undefined condition, prompting individuals to seek answers primarily in the medical context, often referred to as illness (Twaddle 1979: 18) In the early phase, which extends from the onset of motor symptoms to the onset of motor fluctuations (Artusi and Lopiano 2022), many people avoid joining associations. This behavior is often related to the fear of facing individuals in more advanced stages of the disease, a reflection of a possible future that evokes fear. As reported by an interviewee:

At the beginning, I was a bit hesitant, because you know, I was 28 years old, and I knew there were much older people than me, with definitely more serious problems. Fortunately, I don't have major issues right now, but at the start, I didn't want to get involved in this environment. Also, because then people talk: 'I'm like this, you're like that.' In fact, for the first few times, I tried not to join a group, not to get included in any group. (P_7_M_30)

As the disease progresses to an intermediate phase, characterized by motor fluctuations, associations become an essential point of reference. They offer information, peer support opportunities, and practical help to cope with daily difficulties. One interviewee shared:

I have a lot of swallowing problems, like how to swallow a pill without struggling, or issues with my feet. These are all bits of information, even though small, that come from contact with people in the associations. (P_36_F_64)

[2] Each excerpt is accompanied by an anonymous identifier in parentheses, indicating whether the participant is a person with Parkinson's disease (P) or a caregiver (C). The identifier also includes the interview number, the participant's gender, and their age

Finally, in the advanced stage, when therapeutic responses no longer provide adequate functional compensation and severe motor, cognitive, and psychological complications arise (Artusi and Lopiano 2022), associations, beyond sporadic attendance expectations, become a refuge - a place where members can share experiences, feelings, and receive emotional support, as highlighted by a participant:

For example, when I go to the association, I walk in and it's as if I were another person because I feel good. I really feel good with those people. When I go home, I feel more supported and satisfied. (P_43_F_73)

Compensatory activities

Associations prove to be crucial in filling the gaps left by healthcare and social support systems, especially in less-served areas. Through a series of compensatory activities, they respond to critical socio-assistance needs, providing resources and opportunities that would otherwise be inaccessible to people with Parkinson's disease (PD) and their caregivers. These activities aim not only to integrate local services but also to create a support network that fosters the sharing of experiences and knowledge, thus expanding access to information and resources essential for the well-being of the members. Moreover, for both people with Parkinson's and many family members, involvement in associations represents significant emotional and practical support, offering opportunities for connection, socialization, and the sharing of experiences that contribute to their overall balance (Fekonja, Irgolič, and Vrbnjak 2024). As an interviewee emphasized:

And then we're organizing a series of activities that take us all over Italy. That's where our association started. Now we're trying to restart, and we're doing an online course in person together with a neurologist and a psychologist. 12 seminars, one a week, to increase Parkinson's awareness. (P_17_M_72)

I started last year. I've known for two and a half years that I have this disease. There's a lady I know who had her husband, so I came along too, and I feel good here. The teachers and the people are really, really good. The teachers are really great, the psychologist, who is a young woman, is very good, but also the other two are great. But especially this psychologist. (P_26_F_73)

Coping strategies adopted by association members

Another dimension that emerged from the interviews concerns the role of the association in socializing members and providing coping strategies to address the daily challenges of the disease. These strategies represent both practical and psychological support for managing symptoms, improving therapeutic adherence, and planning for the future.

Medical provider selection

Coping strategies for dealing with the symptoms of the disease primarily involve a specific medical provider selection, which is expected to be the same doctor followed by other association members. This desire to have the same doctor is often linked to the need to feel part of a community of patients facing the same condition, sharing experiences and therapeutic solutions. For many members, being followed by the same doctor who treats other association patients not only ensures therapeutic continuity but also creates a sense of cohesion and mutual support. In this case, the doctor becomes a common reference point,

not only for their professional competence but also for the bond they establish with the group of patients who have chosen to follow them. This shared choice of a doctor among association members also offers practical benefits: patients feel more secure and reassured knowing that the doctor has a broad understanding of the disease and its implications for a larger community. Sharing a therapeutic journey with others makes the treatment less solitary and more easily accepted. As one interviewee shared:

I started asking for help from the association. The questions everyone asks: Who do I go to? Which doctor? What is the approach? (P_45_F_60)

In November, we do what many others in the area do: we hold Parkinson's Day. The association provides its facilities and neurologists who share the latest updates and try to inform us about the most recent developments in the field. (C_10_F_44)

Preparatory practices

Another crucial aspect of coping strategies involves preparatory practices. People with Parkinson's and their caregivers adopt proactive measures to manage future activities, aware that the disease's symptoms and the effects of medications can be unpredictable (Abendroth, Lutz and Young 2012). These practices include scheduling medication intake, modifying the home environment to make it more accessible, and mentally and physically preparing to face potential obstacles, such as mobility issues or fatigue. The association plays a key role in this context by connecting individuals at different stages of the disease, fostering the exchange and sharing of experiences. This exchange enables members to prepare for future symptoms or medical, work-related, and relational decisions, drawing inspiration from others' experiences. As one member highlighted:

There are people who, unfortunately for them, have suffered from this disease for many years. I go to ask them: How do you manage to do this, from the very first years until now? How has your perspective or life changed, the symptoms? (P_31_M_67)

Dealing with Stigma

People who participate in the associations, or at least according to their explicit goals, develop strategies to cope with the stigma associated with the disease. For example, using self-deprecating humor as a resilience tool and acquiring knowledge to be prepared are important coping methods. In this context, peer support groups are created, where the term "peer" refers to people with the same condition of illness. These groups allow members to share experiences and challenges, reducing the sense of isolation and excessive attention to one's health status. Such initiatives aim to decrease the shame related to the disease. This is one of the central objectives of the associations, although the collected data shows that the real dynamics are more complex. The interviews reveal that denial or concealment of the disease is more widespread among individuals with higher social status. However, when these individuals become aware of the social implications of the disease, often due to the work done by the associations to change public perceptions, they are more willing to discuss it openly. This shift, from denial to sharing, represents a significant step towards accepting one's condition. As an interviewee noted:

We've attended several courses and socialized, especially by being together, because the association alone cannot do anything. It can't solve the problems of all of us affected by the disease. But the fact of meeting is very important because, in addition to knowing that other people are like us , you don't feel isolated. You don't feel like the only person who's had this misfortune because having diseases is always a misfortune. (P_54_M_81)

Identity expression

The data analysis also reveals that there is no single definition of Parkinson's disease. It manifests in various forms, with differing combinations of symptoms, age at diagnosis, management strategies, pharmacological treatments, and symptom intensity. For instance, there are significant differences in the frequency and severity of freezing episodes, as well as in how patients experience and define their identity in relation to the disease.

The identity definition of people with Parkinson's is articulated in three main interpretive modes, expressed through symbols or evocative phrases that represent what the disease means to those affected:

Parkinson as an unwelcome guest

In this case, Parkinson's is seen as an unwelcome visitor that arrives unexpectedly, prompting those affected to hide or ignore it as much as possible. This approach often leads to efforts to mask or minimize the symptoms. As one interviewee shared:

The monster wanted me, I don't know why it wanted me. (P_1_F_60)

Parkinson is an enemy to fight. (P_38_M_74)

Parkinson as a cohabitant, a roommate

Here, the person's identity and Parkinson's identity coexist within the same body as two separate entities. This dynamic is characteristic of individuals who have come to terms with the disease and acknowledge its permanent presence in their lives. Rather than trying to hide or resist Parkinson's, they accept it as an integral part of their identity and strive to coexist harmoniously with its effects.
One participant said:

Well, I mean well with Parkinson's, because it's no longer like when you didn't have Parkinson's. Feeling well means feeling well with Parkinson's. (P_59_M_75)

Parky, sometimes I scold him and then he scolds me too. Now it's become a sort of game between me and him. It's like having a third brother you can't get rid of, like a Siamese twin. (P_15_M_70)

Parkinson as a dominant identity

Finally, there are individuals who perceive the disease as a dominant part of their identity. In these cases, the disease overshadows their sense of self, becoming the defining feature of who they are and how they are perceived by others. These individuals often introduce themselves by saying *Hi, I'm ___ and I have Parkinson's,* making it a central part of their identity.

As one interviewee expressed:

I was telling you that I have Parkinson's. I've known Mr. Parkinson for a lifetime. (P_17_M_73)

I am ___ and I have Parkinson's.(P_5_M_53)

Discussion

Living with Parkinson's disease profoundly affects social roles, including relationships, family dynamics, and professional life. Symptom fluctuations often disrupt daily routines, leading to withdrawal from roles and altering social interactions (Perepezko et al. 2019). Marital relationships, in particular, may see both positive and negative changes: strengthened mutual commitment for some couples, but also increased responsibilities for the partner, shifts in intimacy, reduced shared activities, and financial strain (Perepezko et al. 2019). These challenges arise as the emotional and physical burdens of being an informal caregiver take their toll (Geerlings et al. 2023).Family roles are similarly reshaped, with the initial communication of the diagnosis playing a key role in fostering acceptance or rejection, impacting coping strategies within the family (Perepezko et al. 2019). Similarly, professional roles are often significantly redefined, with individuals experiencing a reduction in work-related activities. This decline persists despite medical interventions such as pharmacological treatments or deep brain stimulation. The loss of occupational roles contributes to social disconnection, as individuals with Parkinson's tend to organize fewer outings with friends and participate less in recreational activities, favoring solitary and sedentary pastimes.

The variability of Parkinson's symptoms adds further complexity. Without reliable biomarkers, individuals experience significant day-to-day and even hour-to-hour differences in symptom expression and responsiveness to treatment, requiring meticulous planning around medication schedules to manage symptom fluctuations (Riggare 2022). This unpredictability exacerbates the challenges of sustaining social roles and relationships, underscoring the profound impact of Parkinson's on both individual and collective well-being.

Drawing from the principles of interactionism, it's clear that Parkinson's associations are not merely support networks but also pivotal arenas for social interaction and identity formation (Strauss 1959). These *association mirrors* reflect the broader processes described by Strauss (1959) highlighting the role of face-to-face interactions in the constant evaluation of oneself and others. Through such interactions, individuals undergo a dual process of self-assessment and other-assessment, reshaping their identities in the presence of peers, as they present themselves both to others and to themselves, mirroring the judgments exchanged within the group (Strauss 1959).

Thus, the interpretation of the association can be seen as a mirror that, through the combination of these categories, can take on three different types, which vary depending on the stage of the disease the member of the association is in: early, middle, or advanced: Premonitory Mirror, Reflective Mirror, Retrospective Mirror.

Premonitory Mirror

This type is primarily interpreted by those in the initial stage of the disease. These members see the activities carried out by the associations as not aligning with their current condition, often participating with reluctance. Not yet familiar with coping strategies, they view Parkinson's as something to be concealed or masked. In this context, associations are perceived as premonitions of a future reality to which they do not yet feel they belong.

Reflective Mirror

This type of association involves members who have had the diagnosis for some time and have become accustomed to living with the disease. Employing similar coping strategies, they engage in activities deemed beneficial for their condition. They perceive the association as a mirror reflecting their identity, seeking to understand their situation and symptoms through comparison with others. Notably, they observe members in advanced stages to prepare for the progression of their own condition.

Retrospective Mirror

This portrayal presents the association as a commemorative mirror, reflecting memory and experience. It involves *veterans* of coping strategies who deeply identify Parkinson's with their own identity. These members often introduce themselves by saying, "I have been Parkinsonian since…", using the activities organized by the association to reflect on who is the "sickest of them all", or at least sicker than themselves. They engage in activities their condition allows and strive to share their experiences with other members.

This interpretation of associations as mirrors through which members reflect and redefine their identities highlight the importance of these spaces not just as places for practical support, but as dynamic social ecosystems. Associations for individuals with Parkinson's provide more than practical support; they function as dynamic social ecosystems where identities are continually reshaped through interaction, mirroring, and reflection. By fostering recognition, empathy, and shared understanding, these associations offer an invaluable microcosm for navigating the complexities of modern life with a chronic disease. Moreover, associations contribute to preserving roles and identities, which are often challenged by the limitations imposed by motor and cognitive symptoms of Parkinson's disease. These symptoms challenge self-image and disrupt socially constructed notions of femininity and masculinity linked to chronic illness (Fleming, Tolson and Schartau 2004; Simonetto and Tucsok 2023). By acting as mirrors, associations play a key role in helping people with Parkinson reconstruct broader social identities.

Conclusion

In conclusion, this study reflects on how membership in associations serves as an encounter with others, where individuals with Parkinson's can reflect on their past, contemplate the present, and envision the future, significantly influencing their journey of adaptation and acceptance of the disease. Associations provide individuals with the opportunity to maintain their connection to the social fabric, even when their health is compromised by the progression of the disease (Kawachi and Berchman 2014) .

This dynamic aligns with Simmel's concept of reciprocity (1908), which underscores the interconnected nature of social life. Just as societal cohesion is sustained through the mutual exchange of influences among individuals, associations serve as microcosms of this relational dynamic. They facilitate a continuous interplay of shared interests - whether practical or ideal, transient or enduring, conscious or unconscious - through which individuals find unity and purpose. In doing so, associations not only

support their members but also reflect the broader processes of social integration and mutual influence that characterize society as a whole.

Through this lens, associations emerge as spaces where social ties are fostered and redefined, enabling individuals with Parkinson's to navigate their challenges while remaining active participants in the collective social experience.

Limitation

Limitations in this research may be related to sample characteristics, research setting, and researcher bias. The sample was relatively small, and all participants were members of organizations providing support to individuals with Parkinson's disease. This concentration of participants may limit the generalizability of the findings, as their experiences may not fully represent the broader population of individuals with Parkinson's, especially those who do not engage with such associations. Furthermore, while the research setting was isolated from external influences, it may have inadvertently hindered participants from expressing negative opinions about their membership, potentially due to social dynamics within the group. Lastly, as the study was conducted by a single researcher, the lack of multiple perspectives limited the triangulation of the analysis, which could have increased the risk of interpretive bias and reduced the overall validity of the finding.

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