Into the Network: a Qualitative Study on Italian Palliative Care Mindscapes

Roberto Lusardi[1], Joseph Wherton[2], Stefano Tomelleri[3]

[1] Dept of Human and Social Science, University of Bergamo, Italy. roberto.lusardi@unibg.it

[2] Centre for Primary Care and Public Health, Queen Mary, University of London, UK. j.wherton@qmul.ac.uk

[3] Dept of Human and Social Science, University of Bergamo, Italy. stefano.tomelleri@unibg.it

Abstract. This article discusses how symbolic and cultural processes can influence palliative care. These social dimensions are shaped in specific mindscapes and embodied in clinicians', patients' and caregivers' everyday practices. We present methods and results of an action-research programme carried out from autumn to winter 2014. We adopted qualitative network analysis as research method in order to transform mindscapes into symbolic maps. The data consists in 3 interactional maps produced by 26 health and social care professionals. The comparative analysis of maps highlights significant about palliative care networks: a) the power distribution are concentrated around specific networks' hubs; b) the patient-centeredness does not necessarily mean patient empowerment; c) the prevalence of the health system and the persisting of medicalization on social world; d) the loss of the religious prominence on pain and death; e) the 'glue' function acted by the psychologist.

Keywords: Palliative Care; Inter-professional Collaboration; Qualitative Network Analysis; Net-Map.

1. Integration of palliative care practice

The World Health Organisation defines palliative care as *"an approach that improves the quality of life of patients and their families who are facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and correct assessment and treatment of pain, and other problems, whether physical, psychosocial or spiritual"* (WHO, 2013). Rising prevalence of non communicable diseases and an ageing population demands a sustainable public health approach requiring the reconfiguration of services to integrate palliative care into existing health care services and to engage the wider community, by working in partnership. One of the core elements of palliative care is the interdisciplinary team, comprised of clinicians, social workers, volunteers, among others, in order to direct efforts towards the best possible outcomes for patients. Inter-professional collaboration has been shown to improve patient outcomes, such as symptom control, self-determination of end-of-life and care staff satisfaction.

The integrated care model requires inter- and intra-organisational cooperation since multiple services and professionals must collaborate to provide care to the individual. Previous studies into integrated care practices have focused on system models and organizational structures, with a number of studies exploring the role of information and communication technologies to improve communication and co-ordination across services (Bricon-Souf, et al., 2005; van Wingaarden, et al., 2006). While these developments are important, there is strong evidence to suggest a need to look beyond formal structures and processes, to explore the day-to-day experience and collective efforts of those involved in patients' care. A number of studies within the fields of social sciences and sociology have sought to capture actual cooperative behaviors as they happen, revealing important aspects of the nature and requirements of cooperation in healthcare settings (Spence & Reddy, 2012). In the next sections we introduce the application of mindscapes to explore the cooperative networks in palliative care.

2. Imagination, social networks and practices

Scientific literature recognizes that symbolic dimensions can affect care practices, particularly inter-professional collaboration in health care (Morgan & Ogbonna, 2008; Tousijn, 2012). Previous studies have shown the relationship between one's own professional identity and palliative care service quality. Authors have shown how professional identity associated with different clinical roles may be incompatible with the complexity of palliative care networks (Hibbert et al., 2013). The clinician's decision to send a patient to palliative care involves many symbolic and emotive processes which can influence their decision to delay or even withhold the patient's referral through the palliative care pathway, regardless of international guidelines (Kirby, et al., 2014). Such decisions imply a cultural transition from life-prolonging or curative-focused care (e.g. oncological contexts) to life-enhancing care, such as palliative care, that can be critical due to redefinition of professional roles and relationships (MacArtney *et al.*, 2015). Klarara and colleagues (2013), have shown how in the professional interaction with the terminal patient, health workers tend to focus their attention on the patient's *dignity*, the nurses on a patient's *independence* and on everyday functioning, while social workers tend to focus on the patient's *self-image*. All of these symbolic and interactional elements play a significant role on the palliative care quality and efficacy, and therefore, should be understood and scrutinized at the same level as the medical and clinical elements (Greenhalgh, 2014).

This article explores the symbolic dimension of palliative care, in order to investigate how professional practice can be influenced by social and cultural aspects, throughout specific *mindscapes,* embodied in everyday interactions (Maruyama, 1980; 2003). Mindscapes are meanings chains that give structure to the social actors' possibilities for action, giving sense to the everyday practices and orientating relational dynamics. Sleeboom-Faulkner (2013) refers to social mindscapes to explore the ways in which scientists working in genetic laboratories relate their normative ideas on embryonic substances to their work, their non-professional life and their socio-cultural cosmologies. She pointed out that such mindscapes differ from the personal views of individuals. Minsdscapes are intersubjective, established and shared collectviely among a group or community. They are acquired and continually shaped through social interaction, education, upbringing, language and tradition (Hentschel & Sumbadze, 2002).

The notion of mindscapes implies a socially shared manner of thinking and feeling about everyday situations and actions. Consequently, how the social actor imagines their own social network (as rich or poor of relations, with many or few other actors, with some people and not with others), shapes his/her ability to interpret any given situation and act upon it (Berger & Luckman, 1991).

The structure of a social network is first of all a cultural phenomenon and its limits are, in ours case, defined by the ideas of the palliative care network members. From Weick's point of view (1995), the network structure firstly exist in the symbolic representations held by the professional actors; then they exist into their mental map, through which they orient themselves. But whilst it may be perceived by the individual as stable, the mindscape is a fluid construct, which is continually shaped through social interactions in different contexts over time. In mindscapes, the social representations (e.g. culturally defined expectations about a professional role) and individual experience (e.g. personal encounters with professionals) co-exist and co-evolve (Maruyama, 2003).

In this paper, more than focusing on structures and process involved in social network analysis and how they can be analyzed through qualitative methods, already discussed elsewhere (Hollstein, 2011; Heath, Fuller, Johnston, 2009), we intend to show how mindscapes can orient professional action in a specific context: the palliative care. This theoretical question raised during an action-research project devoted to promote inter-professional collaboration in palliative care services in a provincial district in the north of Italy. The three different mindscapes we analyzed here describe diverse ways of imagining the services' networks, the inter-professional relations and the interactions with patient and familiars.

They testify the existence of different contexts of action, in which the participants feel themselves included.

3. Materials and methods

The empirical data presented in this article was collected during a training program for palliative care professionals during October-December 2014, in Bergamo, Italy. This program was organized in collaboration with the Palliative Cares Association, the University of Bergamo and the Local Health Service of Bergamo. The course was part of an action research project intended to create an inter-professional and inter-organisational community to promote cooperative practices across healthcare organizations in the region. The aim of the program was to make explicit the practical, and often subtle, knowledge that is practiced by the actors during every day professional activities of care and assistance. Inter-professional collaboration is embodied in social interaction through time. Therefore, we applied a situated participatory methodology to elicit the complex interactions between knowledge, symbolic dimension and everyday practice (Wenger, 1998).

The symbolic maps presented in this article was conducted during the first module of the course. The process of administering the activities, data collection and feedback lasted 3 hours. The participants were divided in three working groups[1] and had 90 minutes each to draw the maps. The remaining time was used for the plenary discussion of the maps. In total, 26 participants from 17 different care organisations took part at the activities. The sample included: eight doctors, nine nurses, six nurse managers, two psychologists and one volunteer.

The map drawing exercise was based on the network analysis method Net-Map, which has been recognized as a useful approach to understanding decisional processes and social interactions within and between organisations (Schiffer & Hauck, 2010; Waale, 2008).

This technique to develop the interactive maps includes three phases:

1. The identification of the relevant 'hubs' (services, groups or individuals) and their position within the map;
2. The representation of interactions between the hubs, on the basis of the prevalent function conferred. Four functions are possible:
    a. Economical support: every type of economic support for individuals, groups and services.
    b. Technical-logistical support: activities devoted to obtain a specific function into the network (for instance, patient's safety or clinical consulting by specialists);
    c. Informative support: actions of information provision
    d. Moral-psychological support: interactions finalized to provide psychological and moral support (for instance spiritual comfort) to individuals, groups or services.
3. The allocation of counters (small discs) to indicate the 'power' of each hub (the capacity that each of them have to influence the actions of other social actors and the network configuration). Each group had a limited number of counters (50), which they distributed across the network.

Participants collaboratively produced the mindscape in which they perceived themselves to be involved. They were asked to perform this activity as small multi-professional groups in order to facilitate shared learning and discussion as part of the action research (Fig. 1).

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[1] The groups composition was random, letting the choice to the participants. The only criteria imposed was to create inter-professional groups.

Fig. 1 – Working group designing a map

Following the workshop, the raw maps were replicated and analysed using the software tool Visualizer (Version 2.2, Medical Design Logic, 2016). The visual depiction and analysis of the maps incorporated the textual content, as well as the graphical and material composition applied by participants during the three stages described above. In addition, researcher took fieldnotes during the plenary discussion. In the analysis of each map we focused specifically on the shapes, the interactive dynamics, and the power distribution. We then searched for similarities and differences between maps in order to clarify the emergent critical elements

4. Results

The first map (Fig.2) was produced by a group composed by a volunteer, four community nurses (two of them managers), three young specialist doctors and a hospital doctor. This map is densely populated by actors and connections between them. There are numerous hubs, belonging to the health domain, including general practitioners (GPs), hospice, local public health services (ASL), community nurse (ADI), care residence (RSA), health public institutions and others professional categories. The informal components of the network are represented with a similar grade of detail, including friends, benefactors, neighbors, volunteering associations, the priest, welfare workers, and so on. Such complexity and heterogeneity was also stated by the community nurse during the discussions, who reported her difficult experience with multiple and fragmented services and professional groups. However, while there are numerous network connections and functions across both professional and informal members, there is a clear asymmetry when looking at the power distribution (as indicated using the counters). This represents capacity to influence the care process and is visually indicated by the hubs' symbol size (the bigger more power is assigned).

It is evident that the power concentration is different, among health and social actors. The main amount power of influence is located on the regional institutions, the principal network's finance sources. Some social actors (benefactors, third sector associations) also ensure this action, but they obtain only marginal effects. Other significant hubs that are able to modify the patients' care plan are the community nurse services (ADI) and the other roles closer to the patient: the palliative doctor and the nurse. The GP is perceived to have less influence over actions across the network. In the social domain, the volunteer appears to have the most significant influence, whereas other social actors (e.g friends, priest and benefactors) have minimal influence. The social worker was seen to have an important informative role as indicated by the blue lines in Fig. 2.
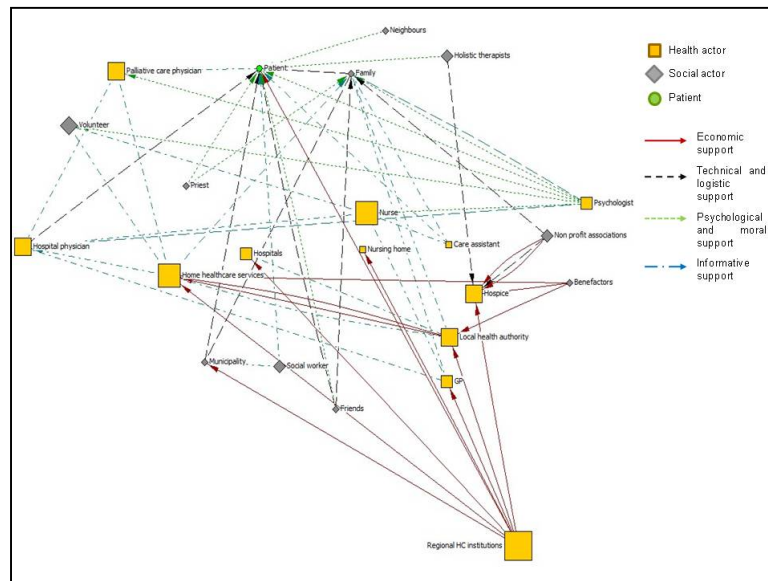
Fig. 2 - *Network n. 1*

The religious sphere, embodied in the priest, was seen to have little influence on the care pathway and his action appears to be limited to function of psycho-moral support. The lack of control of the family is closely tied to another characteristic: the patient (and their family) are the direct and the indirect beneficiaries of most of the represented actors' actions, but the power devoted to them is residual. The patient is scarcely able to actively influence the decisions taken by others actors. Finally, psychologists were not considered to have significant power with regard to palliative care decision. However, this node is characterized by multiple connections within the network, in which they are able to play a significant degree of psycho-moral support for patients and families as well as for professionals.

The second map (Fig.3) was produced by three nurses (two from hospitals and one community nurse), three nurse managers, two hospital doctors and a psychologist. As observed in the previous map, health and social actors are equally represented but we find new elements. For the healthcare domain we see: the addition of emergency ward, emergency response services, district nurse, and simultaneous care service[2]. For the social domain we see the addition of a social worker, informal caregiver and the community assistance service (SAD). We also observe similarities to the previous map with regard to the prevalence and power distribution of health hubs, and so to the capacity of health actors to influence the other network hubs. In particular, a significant concentration is conferred to the actors that finance the network: the regional institutions and the local health company (ASL). Unlike the previous map, the GP takes a dominant position, with direct connections with a great number of hubs. Participants point out the GP's informative function as the 'bridge' and 'translator' between the different medical specializations and the patient. In contrast, the social domain is only partially able to interfere with those passages.

Different social hubs acquire weight. The third sector association, the social worker and the relatives have a certain degree of power, but that which still is inferior to the health domain.

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[2] In patients with potentially terminal illnesses, simultaneous care regards the combined or alternating use of palliative and curative therapies.
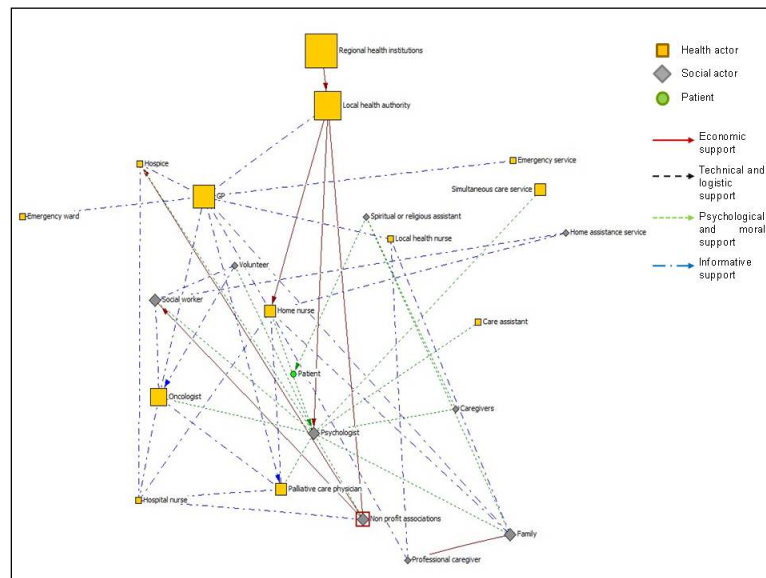
Fig. 3 - Network n. 2

Third sector associations are represented largely for their economic support directed to hospices and social workers. The social worker exercises his/her functions mainly through the community assistance service (SAD) and with the family. The social worker acts as an informative support and orientating other actors to existing services. We have a confirmation of some significant aspects related to the psychologist and the patient. The psychologist is able to connect a significant number of hubs, and in fact, became a network fulcrum, exercising a function of psycho-moral support. With regard to the patient, the central position in the map is not related to the ability of influence the care process. Despite numerous connections, the patient is depicted as presenting very little power. The patient seems imprisoned within the network interactions that make him/her unable to express own wills.

The third map (Fig. 4) has been produced by a group composed by one hospital doctor, one GP, four nurses, one nurse manager and one psychologist[3]. This map purposes an interesting overturning in the capacity of influencing the palliative care process. The patient and his/her family are placed in the middle of the graph and they have the main attribution of power. This time the centrality is accompanied by the ability to influence the care process. The welfare management institutions (State, Region, local institutions) are described as having the principal responsibility for the network funding, both for health and social actors. A similar role is attributed to the third sector associations that operate in the social domain (social workers, pet therapist, music-therapy) and are linked to specific actors of the care network (palliative doctor, simultaneous care doctor, psychologist, specialist doctor). In this third map however, the economic support is not interpreted as mean of authority on the network dynamics. This is in contrast to the previous maps, as it shows a clear disassociation between the economic support and power distribution. We observe again a strong asymmetry regarding the residual power distribution: it is concentrated only in the health hubs, excluding the volunteer, the spiritual assistant and the social worker who have the grade one of power.

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[3]This group had not finished the map as they run out of time. They couldn't assign the techno-logistic and the informative resources. However, this map has been included in the analysis as it provides useful data on the actors involved, the power distribution and the psycho-moral relations.
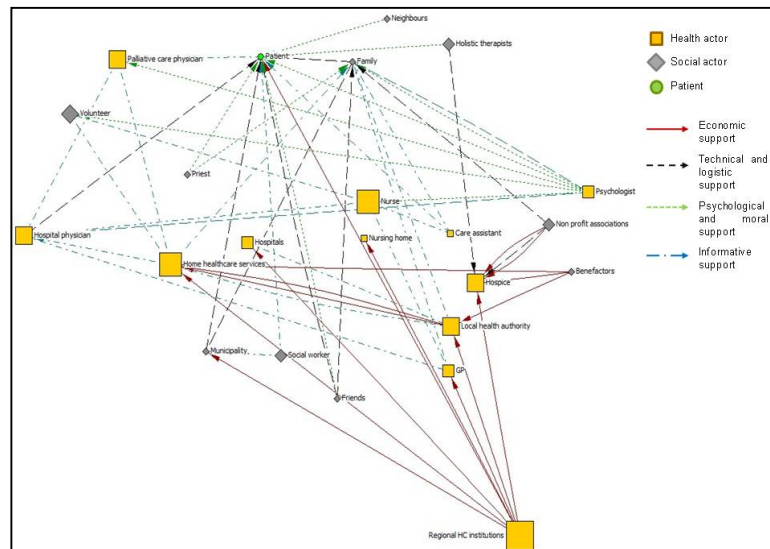
Fig. 4 – *Network n. 3*

The other social actors do not appear to weigh on the network dynamics. In contrast, the GP, the palliative doctor and the nurse have a significant level of power. In addition to power, these three actors also play the linkage function (linking multiple hubs), a role that was attributed to the psychologist in previous maps. In particular, nurses are positioned in the middle of numerous health and social actors.

5. Discussion

This study has collected three different mindscapes of the services, as well as of the social and professional actors' networks that contribute to palliative care. The comparative analysis of the mindscapes reveals important aspects about palliative care practices, that have discussed with the participants in a further formative meeting.

A common characteristic of all maps was that regional and local institutions possess the main power concentration. Therefore they were perceived to have the greatest influence over the network configuration and the inter-professional dynamics. The professionals perceived themselves as parts of an interactive system that they can only partially manage, because the economic support relies on external actors, usually detached from everyday care work. Maps 1 and 2 graphically represent the distance of governance institutions from professional experience. These agencies appeared detached from the hypothetical space of the professional actors' work practice. We confirm the center-periphery distance that has been identified as critical in service articulation (West, et al., 2015).

Personalized and patient-centered care practices are recognized as essential by all health institutions for reaching quality of care. This orientation can be summarized by the sentence "keeping the patient in the center", largely shared in the health domain (Gachoud, et al., 2012). However, the map drawing exercise and the plenary discussions have highlighted that the central position of a patient does not determine their capacity to influence decisions and paths related to their care. Our findings suggest that the effective possibility to accede to the palliative care services may be rooted on rigid and prearranged options, managed by the hubs that detain the most power. This phenomenon is visible in maps 1 and 2, where the patient presents multiple links, upon which s/he has little influence. The claim for a even stronger standardization of practice could partially explain the rigidity that the maps reveal and this aspect was particularly surprising for participants.

The analysis show that the health domain detain the main concentration of power to the detriment of the other social actors (volunteers, social workers, familiars, etc.). The social actors (local institutions, social worker but also neighbors, friends etc.) have minimal visibility in the network, relative to the health hubs. Social hubs that acquire the capacity of influencing the palliative care process are the social worker and the third sector (the latter represented in the maps as volunteers and associations). Social workers manage resources for the community assistance service and the economic support for patients and families. The third sector is viewed as a channel for collecting economic resources and for supplying support actions devoted to patients and families. The maps confirm the persistence of medicalization of everyday life, in which health actors play a dominant role (Conrad, 2007).

In all three maps, the religious dimension related to pain and death was represented as having a marginal role. The loss of influence of the priest role is emblematic of a historical and social process of secularization that is leading to the diffusion of instrumental rationality in every public and private sphere (Bauman, 2013). The maps showed that the influence capacity of the spiritual or religious assistant was considered the same as that of volunteers, friends, and neighbors. In other words, it was residual. The connections with the other network hubs were practically null and limited to the patient sphere. This restraint of the spiritual support and priest's role in the social life is inversely proportional to the centrality of the health role, the regional institutions and the psychologist. The three maps confirm the same phenomenon described in previous literature highlighting the calling for a deep-rooted cultural trend of attribution of the salvific power to the medical science, neglecting her limits, paradoxically also in facing situations of chronic and terminal illness (Conrad, 2007).

The psychologist is a central figure in all maps. S/he represents the fulcrum of dense connections, linking them to all of the significant network hubs. His/her main function consists of psychological and moral support, coherent with their professional mandate. However, the psychologist's high degree of interconnections is also crucial for informal coordination and knowledge sharing across the network. This function is facilitated by the fact that s/he is represented as a hybrid within the health and social domain: maps 1 and 2 depict the psychologist as having a health role, while map 3 represents them as belonging to the social domain. This suggests that the psychologist is seen to act in both domains, and his/her authority is also recognized in both domains. This hybrid characteristic is also common for the GP who is perceived as the bridge from the patient's everyday life and the health services. However this function of the GP was not visually depicted in all three maps. Only in map 2, was the GP presented with a significant rate of interconnections. In the other two maps he/she does not appear as directly connected with the rest of the network. The centrality of the psychologist can be explained with the loss of symbolic importance of social figures (politicians, priests, and so on) that historically played this linking function (Bauman, 2013). Another cause could be found in the difficulties that GPs are facing in managing palliative care (Beccaro, et al., 2013).

6. Conclusion

This article shows the different representations of the palliative care network in the province of Bergamo, in the north of Italy. The symbolic dimension of palliative care has been explored in order to investigate how professional practice can be influenced by social and cultural aspects, throughout specific *mindscapes,* embodied in everyday interactions. Mindscapes analysis helps to understand how the social and health actors perceive their working contexts and inter-professional interactions. Although some aspects of the data are incomplete, the elements discussed in this article are still relevant. The purpose of the maps was to obtain the subjective interpretations and everyday experience of the participants, rather than obtain a factual account of the palliative care process and organizational structures. We believe that the findings highlight the potential application of

mindscapes and qualitative network analysis to elicit intra- and inter-organisational interactions beyond those represented within formalized structures and processes. In addition, we think that the results of this study can help inform future empirical investigations into the coordination and involvement of people and services within palliative care practice. Future research could also explore the similarities and differences of maps produced from different regions or local territories, with different services and cultures. This comparison would highlight typical features of national health systems and could help identify and promote good practice within care settings.

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