


# Caregivers' engagement during in-hospital care of sABI's patients: Evaluation of informal co-production from the health providers' perspective

Maria Luisa Farnese PhD<sup>1</sup>  | Giovanna Girardi PhD<sup>1</sup> | Roberta Fida PhD<sup>2</sup> |  
 Umberto Bivona PhD<sup>3</sup> | Michelangelo Bartolo MD<sup>4</sup> | Antonio De Tanti MD<sup>5</sup> |  
 Domenico Intiso MD<sup>6</sup> | Federico Scarponi MD<sup>7</sup> | Gabriella Antonucci MS<sup>1,3</sup>

<sup>1</sup>Department of Psychology, Sapienza University of Rome, Rome, Italy

<sup>2</sup>Norwich Business School, University of East Anglia, Norwich, UK

<sup>3</sup>IRCCS Fondazione S. Lucia, Roma, Italy

<sup>4</sup>Neurorehabilitation Unit, Department of Rehabilitation, HABILITA, Bergamo, Italy

<sup>5</sup>Istituto S. Stefano Riabilitazione, Centro Cardinal Ferrari, Fontanellato (PR), Italy

<sup>6</sup>UOC di Medicina Fisica e Riabilitativa, IRCCS Casa Sollievo della Sofferenza, San Giovanni Rotondo (FG), Italy

<sup>7</sup>Ospedale San Giovanni Battista, Foligno (PG), Italy

## Correspondence

Maria Luisa Farnese<sup>\*</sup> Department of Psychology, Sapienza University of Rome, Rome, Italy.  
 Email: marialuisa.farnese@uniroma1.it

## Abstract

One of the challenges of providing healthcare services is to enhance its value (for patients, staff and the service) by integrating the informal caregivers into the care process, both concretely managing their patient's health conditions and treatment (co-executing) and participating in the whole healthcare process (co-planning). This study aims at exploring the co-production contribution to the healthcare process, analysing whether and how it is related to higher caregivers' satisfaction with service care and reduced staff burnout, in the eyes of the staff. It also investigated two possible factors supporting caregivers in their role of co-producers, namely relationship among staff and informal caregivers related to knowledge sharing (i.e. an ability determinant supporting co-production) and related to role social conflict (i.e. a willingness determinant reducing co-production). Results of a structural equation model on a sample of 119 healthcare providers employed by neurorehabilitation centers in Italy with severe acquired brain injury confirmed that knowledge sharing positively related with caregivers' co-executing and co-planning. Also, social role conflict was negatively related with co-executing but positively with co-planning. Furthermore, co-planning resulted in being unrelated to both outcomes, whereas co-executing was associated with caregivers' satisfaction, as measured by staff perceptions. Overall, our data provided initial empirical evidence supporting the ability of the determinant's contribution in allowing informal caregivers to assume an active role in both co-production domains. Furthermore, as expected, the role of conflict willingness determinant was found to be a hindering factor for co-executing but, conversely, a trigger for co-planning. This result should be considered more carefully in future studies.

## KEYWORDS

acquired brain injury, co-production, health professionals, informal care

## 1 | INTRODUCTION

Severe acquired brain injury (sABI) is defined as central nervous system damage due to acute traumatic or non-traumatic (e.g. vascular, anoxic, neoplastic or infective) causes, that leads to a variably prolonged state of coma (Glasgow Coma Scale  $\leq 8$ ). Because of its potentially wide range of impairments that affect physical, cognitive and/or psychological functioning (Laver et al., 2014; Zampolini et al., 2013), sABI is a major cause of long-term disability, with an estimated incidence of approximately 73 cases per 100,000 people (on a total of 5.48 million people) each year in the world (Dewan et al., 2018). Rehabilitative management of persons with sABI is one of the most complex challenges of modern rehabilitation, and no other disability condition requires such a huge investment of human, technological and structural resources (Oberholzer & Muri, 2019; Zampolini et al., 2013).

The consequences of sABI are known to affect not only the patients themselves but also their families. Indeed, regardless of the severity of the injury, family members often feel high levels of strain both in the in-hospital admission and in the discharge phases because individuals with sABI are for the most part unable to manage their social life and dramatically depend on them (Bivona et al., 2015; D'Ippolito et al., 2018; Koskinen, 1998; Kratz, Sander, Brickell, Lange, & Carlozzi, 2017; Kreutzer et al., 2018; Rand, Malley, & Forder, 2019). The higher risk of strain is, anyhow, for the family member (a relative or a close friend) who acts as an informal caregiver (hereafter, IC) and specifically cares for the loved one with significant health issues, through voluntary and unpaid help, regardless of their experience or specialised knowledge (Spann et al., 2019).

Informal care is getting increasing attention in European countries (Haley et al., 2019; Pindus et al., 2018). In Italy, individuals with sABI usually stay in intensive care unit (ICU) or neuroIntensive care unit (NICU) until their clinical condition is stabilised and are admitted to rehabilitation wards or discharged. To date, the modality of IC engagement is still debated and managed differently by health units across the country, offering a fragmented picture and eliciting a feeling of loneliness in ICs in taking charge of their loved one.

To our knowledge, only few studies aimed at appraising whether ICs may represent a resource for the service, for instance in terms of costs and benefits for the improvement of health services (van den Berg, Brouwer, & Koopmanshap, 2004; Koopmanshap, van Exel, van den Berg, & Brouwer, 2008). Furthermore, research focused mainly on the ICs contribution in the post-discharge phase (Bartolo et al., 2016), neglecting their role in the in-hospital phase.

The lack of empirical work on the co-creation process (Payne, Storbacka, & Frow, 2008) does not allow to ground policies on a sound framework. This study purposed to provide initial evidences to help health organisations design and manage a charge process of these patients having low autonomy, involving ICs also in the in-hospital phase. Specifically, its first aim was to verify whether and how IC co-production is perceived as useful for the service, contributing to the ICs' satisfaction with the service care and to healthcare provider's burnout reduction. Furthermore, we sought to understand

### What is known about the topic

- Family caregivers provide voluntary and unpaid help, regardless of their specialised knowledge and motivation for care-giving.
- Few studies on informal co-production in the in-hospital phase.
- Health services often unacknowledged family caregivers' contribution.

### What the paper adds

- Focus on specific co-producing processes during in-hospital healthcare.
- Initial evidence for co-executing contribution for healthcare services; need for further studies on co-planning.
- Information sharing and low role conflict among staff and caregivers are relevant determinants for co-production.

the role of some practices (i.e. knowledge sharing and role clarity) in supporting ICs' active co-production.

## 1.1 | Theoretical framework and hypotheses

The Healthcare Services, similarly to other kinds of service organisations, increasingly outsource part of the care interventions to their direct (patient) or indirect (family) clients-users, thus enhancing interaction and proximity between patients and staff (Humphreys & Grayson, 2008). When actively involved in providing a service, clients assume the role of 'pro-sumers', which is being at the same time consumers and (co) producers of the care service (Toffler, 1980). Specifically, ICs may participate in daily activities, concretely supporting patients' health conditions and treatment, for example, helping patients with meals, getting out of bed, transferring between departments for specific therapies, while also providing emotional support and supporting patient's treatment compliance. This is what is called *co-executing* (e.g. Laitinen, 1993; Sapountzi-Krepia et al., 2006). To a wider extent, IC can also be involved in the design of the healthcare process (and of the service), for example, contributing to the treatment planning and decisions, making suggestions for the service design improvement or evaluating its quality (e.g. Gilardi, Guglielmetti, Marsilio, & Sorrentino, 2016; Ranjan & Read, 2016; Realpe, Wallace, Adams, & Kidd, 2015). This IC engagement is referred to as *co-planning*.

## 1.2 | The informal caregivers contribution to the care process

Some research has shown that, when Health Services consider caregivers a resource for the healthcare process and involve them in the care-treatment process, organisational effectiveness and efficiency

improved, positively affecting the sustainability of the health system (van den Berg et al., 2004; Hibbard & Greene, 2013; Koopmanschap et al., 2008; Lee & Lin, 2010). Specifically, it seems to have an impact on the treatment efficacy, for instance through improving patients' adherence to the treatment, ensuring continuity of care, helping to monitor and manage the clinical and personal care problems and dealing with emergencies and recognising the symptoms of aggravation early (Hibbard & Greene, 2013; Sebern & Riegel, 2009).

ICs may actively participate in all of the different phases of healthcare intervention: for example, during the disclosure of the disease or pathology to the patient, in the assessment of the patient's discharge, in managing post-hospital care, and in motivating patients to engage in treatments over time (Sebern & Riegel, 2009). Some studies focused on the role ICs play in the phase subsequent to the patient's discharge and on how facilities can support them (e.g. by information, training, counselling or social support; Visser-Meily, Post, Schepers, & Lindeman, 2005) anyhow none, to our knowledge, have focused on their role during the hospitalisation phase.

This early phase is crucial for successful treatment. Thus, the first aim of the present study is focusing on this neglected phase, exploring the possible contribution of ICs to implement it. Based on the literature, which suggest that co-production may contribute to the overall service effectiveness, we assume a positive association of the active role of IC in co-production with positive outcomes for the health service. Specifically, sABI represents a highly stressful event that affects family members (directly) and the staff (vicariously) that causes resource lost (e.g. affective conditions, social status, energies). Drawing on the Hobfoll's (2011) Conservation of Resources (COR) theory, the possibility for ICs to actively contribute to their patient's care represents a way to proactively cope with a threatful situation, trying to exert higher control on it. That is, they invest resources in order to limit loss of resources or protect them (Farnese, Fida, & Picoco, 2020; Hobfoll, 2011). Consistently, we hypothesised that when ICs are active in co-production (in both co-executing and co-planning domains) they will also experience higher satisfaction for care, in the staff perception (H1a, H1b).

Furthermore, we assumed that ICs could represent a social-support resource for the staff, providing concrete help (co-executing) but also showing co-responsibility in the healthcare process (co-planning). Indeed, clients' participation in the service production/design is based on mutual exchange, sharing of knowledge and ideas and collaboration experiences that contribute to the staff perception of support, shared ownership of the process and value co-creation (Payne et al., 2008; Ranjan & Read, 2016). In the COR framework, social support is a major vehicle by which personal resources can be widened outside the individual's domain, thus we hypothesised that ICs are active in both co-production domains and are related to reduced staff burnout (H2a, H2b).

### 1.3 | Factors for informal co-production

Our second aim is to verify the role of the organisational factors that may promote ICs' participation in the healthcare process, making

them effective co-producers. Previous research has identified two main factors that may support caregivers in assuming an active role. The first type of factors includes *ability determinants*, related to the information knowledge and skills necessary to co-produce (Merz, Czerwinski, & Merz, 2013). Accurate and honest health instrumental information related to recovery are not only the important unmet need of ICs in inpatient rehabilitation setting after a brain injury, as shown by studies using the care Family Need Questionnaire (Doser & Norup, 2014; Kreutzer et al., 2018; Schaaf et al., 2013), but also a necessary requirement for co-production. Indeed, reduction of information asymmetry through dialogue, transparency, access to information and clearly assessing the risks and benefits of decisions are identified as the building blocks for co-production (Pralhad & Ramaswamy, 2004). Here we examined the role of staff information sharing, given that the increase of information, knowledge and skills in ICs may facilitate their interaction with the health services and enable ICs to better perform their co-producer function (Kjellström, Norrving, & Shatchkute, 2007). Specifically, we hypothesised that information sharing will be positively associated to both co-executing (H3a) and co-planning (H3b) domains, paving the way to positive outcomes in caregivers' satisfaction (H3c) and reduced staff burnout (H3d).

The second type of factors involves *willingness determinants* and are related to motivational factors such as perceived control, risk in participating in decision-making, quality of relationship necessary to engage in co-producing behaviours and reasons for care-giving (Merz et al., 2013; Rand et al., 2019). Motivational factors are prominent preconditions for co-production because people voluntarily choose to invest their time and effort, combining their work with unpaid care, thus actively contributing to services, which are the responsibilities of professionals (Spann et al., 2019; Verschuere, Brandsen, & Pestoff, 2012). Indeed, understanding how to perform a role encourages cooperation and provides a positive reinforcement to engage in problem-solving processes and fulfil mutual desires-expectancies (Schneider & Bowen, 1985; Zeithaml & Bitner, 2000), leading to higher self-esteem and a sense of accomplishment. Engagement in interacting and constructive participation also raises the possibility of generating solutions (Ranjan & Read, 2016). On the other hand, lack of role clarity makes co-production less effective and increases the perception of uncertainty because of performing an unstructured process or heightens the risk of poor self-performance (Etgar, 2008; Prahalad & Ramaswamy, 2004). Furthermore, stressful staff-patient interactions, such as conflicts or aggressive acts by patients or family members, have been negatively related with the care effectiveness and the well-being of patients, caregivers and health staff (Needham, Abderhalden, Halfens, Fischer, & Dassen, 2005), being also related with a loss of resources that is known to represent a main cause of burnout (Hobfoll, 2011).

Here we examined the role of social conflict that is disproportionate or ambiguous customer expectations, customer verbal aggression and disliked customers (Dormann & Zapf, 2004). We specifically hypothesised that role social conflict will have a negative association with co-executing (H4a) and co-planning (H4b) and that

overall will be positively associated with ICs' satisfaction (H4c) and staff burnout (H4d).

Figure 1 presents the graphical representation of the whole hypothesised model.

## 2 | METHOD

### 2.1 | Participants and procedure

The current research is a preliminary study, part of a wider multicentric research project aimed at attaining a picture of the current IC–healthcare provider relationships in Italy. To ensure the homogeneity of particular clinical and contextual factors, facilities dedicated to the treatment and rehabilitation of the same type of patients with sABI were included in the study (Kratz et al, 2017, Norup, Petersen, & Mortensen, 2015). Five centres in Italy supplied by neurorehabilitation and ICU/NICU units voluntarily took part in the research. For each unit, management and its local referent co-ordinated data collection, and its entire staff were asked to participate.

Staff members were informed that participation was voluntary, that responses would be kept confidential and anonymous and that data would always be reported in an aggregate form. They completed a paper and pencil questionnaire individually, after which the data were transferred to an electronic database. The study was approved by the local ethics committee (CE/PROG. 555-2016) of the centres taking part in the study. The study was conducted in accordance with the revised version of the Helsinki Declaration.

Participants included 119 staff members employed by five Italian public health structures (HA  $n = 27$ , HB  $n = 18$ , HC  $n = 24$ , HD  $n = 29$  and HE  $n = 21$ ). Participants represented different professions (doctors 10%, nurses 28%, physiotherapists 31%, speech therapists 19%, psychologists 9%, health workers 20%, others 2%), were mainly female (73%), middle-aged (<30 years = 11.9%, 31–45 years = 50.0%, >46 years = 38.1%), and old-tenured (1–5 years = 16.4%, 6–15 years = 39.7%, 16–30 years = 35.3%, >31 years = 8.6%).

### 2.2 | Measures

*Information sharing* was measured by Bunderson & Sutcliffe's scale (2002), adapted to the health context. It taps deliberate attempts on

the part of staff members to exchange care-related information and keep ICs apprised of treatment, key developments and decisions. It includes nine items (e.g. 'When a problem arises in the treatment–rehabilitation process, the staff informs the family-caregiver'). Response options ranged from 1 = *never or almost never* to 5 = *always or almost always*. Internal consistency in the current sample was 0.92.

*Role social conflict* was measured with seven items from the disproportionate customer expectation dimension of the customer-related social stressors scale by Dormann and Zapf (2004). It assesses caregivers' attitudes and behaviours challenging what is considered reasonable and acceptable from the health service provider's point of view (e.g. 'Some caregivers demand special treatment'). Response options ranged from 1 = *never or almost never* to 5 = *always or almost always*. Internal consistency in the current sample was 0.79.

*Informal caregiver co-production* was measured by a new scale, composed of two dimensions related to the different roles that ICs may play (Gilardi et al., 2016). The *co-executing* dimension includes six items generated from Laitinen (1993) and Sapountzi-Krepia et al.'s (2006) checklists. They describe daily care-giving activities provided by family members in health settings (e.g. 'Body care –e.g. facial cleansing, change of clothes'). The *co-planning* dimension involves six items generated from ICs' contribution to service design and evaluation (Gilardi et al., 2016). Items are related to participation in treatment decisions, service planning and service or health policy evaluation (e.g. 'Provides suggestions to improve the service'). For both dimensions, response options ranged from 1 = *never or almost never* to 5 = *always or almost always*. Internal consistency in the current sample was 0.74 and 0.77 respectively.

*Perceived ICs' satisfaction with quality of service care* was measured by two items based on Aiken and Patrician (2000) studies. They tapped professionals' perceived quality of care related, respectively, to ICs' satisfaction with the care treatments their patient received and with their relationship with the staff members. Response options ranged from 1 = *not at all* to 5 = *at all*.

*Staff burnout* was measured by five items assessing the emotional exhaustion dimension of the Burnout scale (Maslach et al., 1996), referring to the depletion of an employee's internal resources, leading to feelings of emotional and physical fatigue (e.g. 'I feel emotionally drained from my work'). Response choices ranged from 1 = *not at all* to 5 = *at all*. Internal consistency in the current sample was 0.88.

### 2.3 | Statistical analysis

As preliminary analyses, descriptive statistics and correlations were performed using SPSS version 24 (IBM, 2016). The posited model was examined by using structural equation modelling (SEM) analysis in Mplus 8.2. The measurement model was tested as first step to examine its adequacy (Bollen, 1989). In line with Harman's recommendation (1976), common method bias was checked by comparing the measurement model with an alternative one factor model with all the indicators loading onto a single factor.

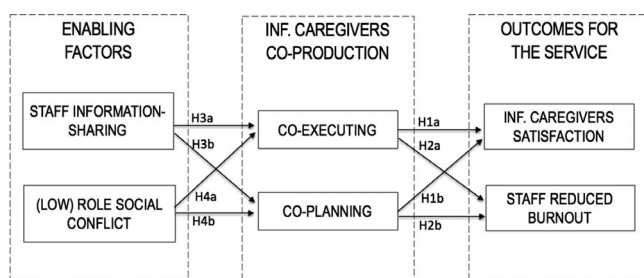


FIGURE 1 The hypothesised model

When testing the posited model, all dimensions were defined as latent variables. Given the small sample size, information sharing, role social conflict and co-production dimensions were defined by parcels (i.e. the average of several items measuring the construct) that reflected latent variables (Coffman & MacCallum, 2005). Burnout and perceived caregiver satisfaction were measured by their respective items. To test the indirect effects, we used the test implemented in Mplus 8.2 and computed the bootstrapped confidence intervals.

### 3 | RESULTS

#### 3.1 | Descriptive statistics

Table 1 presents the descriptive statistics and correlations of the study variables. All variables were normally distributed. The analysis of the correlations showed that information sharing was correlated with co-planning and perceived caregiver satisfaction; role social conflict was associated with both co-production dimensions, co-executing and co-planning; and co-executing was significantly correlated with perceived caregiver satisfaction. Emotional exhaustion did not correlate with any of the variables.

#### 3.2 | Posited model

The results of the measurement model supported a good fit of the model:  $\chi^2_{(137)} = 211.48$ ,  $p < .01$ ; CFI = 0.92; RMSEA = 0.068 (90% CI = 0.049–0.085,  $p = .059$ ; SRMR = 0.067. The one-factor model demonstrated a poor fit to the data:  $\chi^2_{(152)} = 801.28$ ,  $p < .001$ , CFI = 0.33, RMSEA = 0.189 (90% CI = 0.177–0.202),  $p = .001$ ; SRMR = 0.184, providing support for the discriminant validity of the scales and the absence of common method bias.

Results of the posited model are presented in Figure 2. The model showed a good fit:  $\chi^2_{(138)} = 206.77$ ,  $p < .01$ ; RMSEA = 0.065 (90% CI = 0.046–0.082),  $p = .097$ ; CFI = 0.93; SRMR = 0.063. It confirmed a significant association between the considered determinants and the two co-production domains. Indeed, the *ability*

*determinant* (information sharing) was positively related to co-executing and co-planning. It also showed a positive relationship with the perceived caregivers' satisfaction.

The *willingness determinant* (role social conflict) showed a negative association with co-executing, whereas an unexpected positive relationship with co-planning emerged. Thus, when perceived, ICs' expectations are consistent with staff roles, and this supports concrete collaboration in care activities; when IC's expectations are perceived as disproportionate, this supports higher IC engagement in treatment decisions and in providing feedback on service designs. In addition, results showed that role social conflict was negatively associated with caregiver's satisfaction indirectly through co-production ( $\beta = -0.14$ , bootstrap CI:  $-304$ ;  $-0.010$ ). Furthermore, co-planning was not related, in the staff's perspective, to either outcome. Finally, none of the co-production dimensions were related to burnout.

### 4 | DISCUSSION

This study aimed to provide initial evidence for the contribution of ICs to the healthcare process in the in-hospital phase. Specifically, it focused on the different role ICs may play in this process and on whether and how integrating ICs in co-executing and co-planning functions adds value for health services.

Results provided support for most of the hypothesised paths. First off, staff commitment in sharing information with ICs was positively related to their active participation through co-executing and co-planning. Indeed, the more staff provided ICs with prompt and accurate information about the patient's care and treatment and keeping them updated regarding key decisions, the more the caregivers actively participated in the care treatment process, in both its delivery and design. Furthermore, staff information sharing was related to perceived ICs' satisfaction both directly and through the ICs' concrete participation with their patient's care (co-executing), whereas it was not related to staff well-being (reduced burnout). In other words, the ability determinant, namely providing ICs with information and the skills necessary to co-produce, demonstrates a pattern that paves the way to higher collaboration with health services, both in its delivery and design. These data are consistent with

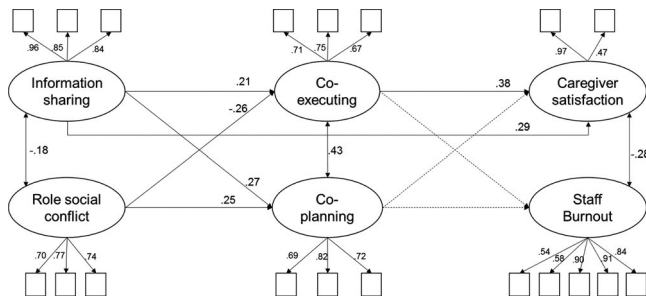
**TABLE 1** Descriptive statistics

	M	SD	Skewness	Kurtosis	2	3	4	5	6
1. Information sharing	3.829	0.810	-0.787	0.434	-0.129	0.175	0.198*	0.007	0.248**
2. Role social conflict	3.180	0.553	-0.458	0.012	1.000	-0.204*	0.219*	0.175	-0.111
3. Co-executing	2.941	0.626	0.069	0.215		1.000	0.250**	-0.061	0.273**
4. Co-planning	3.038	0.614	-0.394	0.521			1.000	0.129	0.063
5. Emotional Exhaustion	2.333	0.935	0.570	-0.495				1.000	-0.183*
6. Perceived caregiver satisfaction	3.312	0.597	0.025	0.342					1.000

\* $p < .05$ .

\*\* $p < .01$ .





**FIGURE 2** Results of the posited model. All the coefficients are standardised and significant for  $p < .05$ . Dashed lines refer to non-significant paths

the Italian Consensus Conference on ABI (Taricco, De Tanti, Boldrini, & Gatta, 2006) that has already recommended team communication and psychological support to families.

A concrete collaboration, in turn, was related to higher satisfaction with the quality of the treatment. This result is in line with the COR theory (Hobfoll, 2011), assuming that those individuals with greater resources are less vulnerable to resource loss and more capable of resource gain. On the other hand, ICs' co-production was not related to staff reduced burnout, neither relationships emerged between co-planning and both outcomes. Thus, the staff seemed to conceive the ICs' concrete participation as a tool for higher satisfaction with the service, but not for their own well-being. Following Hobfoll (2011), we can suppose that borrowing resources from others is not enough to balance own loss, with loss being more salient than gain. We can also assume that staff may perceive co-planning as a demanding relationship, rather than a supporting one. If this is the case, future studies should explore whether the not supported effect of co-planning on increased staff burnout may be due to different factors, more salient in the eyes of the staff (e.g. workload), or for instance to an ambivalent perception of ICs' contribution (both helping and demanding). For instance, they may assess ICs' overall support in co-production (balancing the co-planning possible critical issues) or suppose that even co-planning could be a useful contribution within clearer role or practices boundaries. Thus, health services should invest time and resources in implementing protocols to also make co-planning a co-production way through which ICs positively contribute to the treatment process.

The willingness determinant (role social conflict), consistent with our hypothesis, was negatively related to co-executing. That is, the more ICs are perceived as having disproportionate expectations, the less they are willing to engage in co-operative care behaviours. Conversely, it was positively related with co-planning. We may presume that the more the staff feel ICs' attitudes and behaviours are not aligned with expected roles, the more they perceive caregivers as active in the design of the care treatment process (likely, to change it) failing to be a resource for the service. Overall, these initial results on the co-planning domain require additional examination. Furthermore, the willingness determinant had no direct relationship with staff burnout, thus it does not seem to be a stressor for health providers (Dormann & Zapf, 2004). Future research should explore

this lack of association that may be due to the specificity of patients (e.g. the severity of their injury could make professionals more tolerant and sympathetic with their families or better trained to cope with potentially demanding behaviours) or to the reduced sample size.

#### 4.1 | Theoretical implications

Results of this study demonstrated that the two caregiver participation domains (co-executing and co-planning) had a different network of relationships with both the ability-motivation determinants and the outcomes for patients and staff. Overall, they indicated that the relationships may be somewhat more complex than the literature suggests, highlighting that the quality of co-production implies specific ways of operating and interpreting one's role, through a negotiation process rooted in different motivational and ability assets. Specifically, when ICs are provided with the necessary information and skills to perform their role, and have role clarity, they are also more engaged in co-production, concretely supporting treatment and contributing to service improvement. They participate in an 'integrative logic', that is, they act as resource integrators, contributing to the service value creation (Lusch & Vargo, 2006).

Nonetheless, this is a dynamic and awkward process (Prahlad & Ramaswamy, 2004). When a failure in role definition occurs, it can lead ICs to lose confidence in professional health providers and existing service procedures, to reduce their willingness to collaborate (co-execute) and to exert their co-planning function in a critical way, for instance by proposing alternatives to standard procedures and routines or expressing negative feedback. The IC's contribution in co-planning does not represent a resource for the staff well-being neither leads to higher satisfaction with the service's quality. We may say that ICs participate in a 'replacement logic', that is, they use their resources in a way that is complementary to those of the service, which does not recognise ICs as value co-creators. This emerging double path provides a starting point for future research to explore possible models of co-production and related factors and highlights the need to examine whether the co-planning function may have an impact on different outcomes, for instance related to wider service effectiveness.

An alternative explanation of this result may be traced back to the challenging proposal by Plé and Cáceres (2010). Contrary to the optimism regarding the benefits brought by co-production, the authors argue that the involvement of users in the healthcare delivery process may entail value co-destruction, rather than value co-creation (see also, Palumbo & Manna, 2018). In particular, value co-destruction is likely to happen when actors (either the user, the health provider, or both) participate in the design and delivery of services adopting conflicting perspectives, bringing incongruent inputs, and aiming at the achievement of diverging ends (Smith, 2013). The risks in the co-production process is particularly high, caregivers usually lacking the knowledge, skills or experience to be effectively involved in health service co-production (Teunissen, Visse, & Abma, 2015). In addition, healthcare professionals may play a significant role in value co-destruction when they are requested to adopt a user-centred approach

to care. Indeed, they may tend to limit the involvement of caregivers, due to the fear of losing control on clinical decisions (Owens & Cribb, 2012) or because influenced by the traditional bio-medical paradigm which, different from a psychosocial one, still neglects the users' role in health services' design and delivery (Wood, 2012).

## 4.2 | Practical implications

Some authors have highlighted that the co-production process is a dynamic and interactive relationship between the provider and the customer, where each actor invests knowledge, time and emotions in the collaboration experience (Payne et al., 2008). However, this is an emerging process and scholars have suggested that organisational contexts may support it by identifying good practices and management tools to help create value (Etgar, 2008; Payne et al., 2008; Prahalad & Ramaswamy, 2004). Our study in the Italian country shows that the two co-production domains are distinctive, and for policy makers there is value in assessing both co-executing and co-planning. The operationalisation we proposed, consistently with proposals in other countries (for a review see Merz et al., 2013), could help health services to monitor co-production practices, for instance by analysing their frequency in relation to the adoption of specific organisational procedures (e.g. hospital units with limited or free access for families), or comparing staff and informal caregivers' perspectives.

This study also demonstrated how two possible determinants, related to ability and motivation (Merz et al., 2013), may differently support the co-production process. For instance, focusing on the *ability* determinant allows the management of health services to implement guidelines and practices aimed at enhancing a transparent and trustworthy information exchange among staff and ICs, such as defining 'information steps in the treatment process, places for meetings with families, training sessions for ICs, listening points or tools, monitoring near-miss and failures (Prahalad & Ramaswamy, 2004). Focusing on the role clarity *willingness* determinant, allows management to provide ICs with clear guidelines on how to engage with care activities, clarify the specific contribution of each professional in the service, organise workshops to enhance engagement in co-production activities or even develop infrastructures for resolving conflicts among actors (Verschuere et al., 2012). In general, following some authors' suggestions, policy makers may emphasise the importance of creating a cultural framework that allows co-production to be enacted, for instance by promoting a learning culture where the supplier-customer interaction provides the opportunity to create a better service (Farnese et al., 2019; Payne et al., 2008), establishing the emotional precondition to co-operate (e.g. trust, empathy; Etgar, 2008), and supporting the values, norms and patterns of behaviour sharing (Etgar, 2008).

## 4.3 | Conclusions and limits

This study provides some initial evidence on how family caregivers may contribute to the effectiveness of health services.

Nevertheless, this is a preliminary study with limitations due to the reduced number of participants and its correlational design and to the reduced number of participants that did not allow investigating differences among the different roles. Further studies should specifically address the possibility that each type of professional may differ in the ways and intensity of their involvement in co-production.

Furthermore, we chose sABI patients given their complete dependence on their family's help. If, on one hand, this allowed to consider a homogeneous clinical condition, where the role of the IC is particularly evident, on the other hand, future research should contribute to the generalisability of these results overcoming the specificity of these patients' injuries. For instance, given the severe nature of brain injury and the complete dependence of sABI patients, we could not highlight possible interactions between patient's engagement in treatment and contribution of their caregivers. Moreover, a multi-source design (including the caregivers' point of view) could help consider different perspectives on the co-production process. Also, a multi-centre design would allow the comparison of practices in use in different health services.

## ACKNOWLEDGEMENTS

We gratefully acknowledge the commitment of the participants and their families in the pursuit of research on stroke disease. This research included the advocacy of SIRN, the Italian Society for Neurological Rehabilitation.

## CONFLICT OF INTEREST

Authors declare that they have no conflict of interest. The study was approved by the local ethics committee of the centres taking part in the study (Santa Lucia Foundation, CE/PROG.555). All authors have seen and approved the manuscript being submitted. The article is the authors' original work, has not received prior publication and is not under consideration for publication elsewhere.

## ORCID

Maria Luisa Farnese  <https://orcid.org/0000-0001-7493-9772>

## REFERENCES

- Aiken, L. H., & Patrician, P. A. (2000). Measuring organizational traits of hospitals: The Revised Nursing Work Index. *Nursing Research*, 49(3), 146–153. <https://doi.org/10.1097/00006199-200005000-00006>
- Bartolo, M., Bargellesi, S., Castioni, C. A., Bonaiuti, D., Antenucci, R., Benedetti, A., ... Colombo, C. (2016). Early rehabilitation for severe acquired brain injury in intensive care unit: Multicenter observational study. *European Journal of Physical and Rehabilitation Medicine*, 52(1), 90–100.
- Bivona, U., Formisano, R., De Laurentis, S., Accetta, N., Rita Di Cosimo, M., Massicci, R., ... Costa, A. (2015). Theory of mind impairment after severe traumatic brain injury and its relationship with caregivers' quality of life. *Restorative Neurology and Neuroscience*, 33(3), 335–345. <https://doi.org/10.3233/RNN-140484>
- Bollen, K. A. (1989). *Structural equations with latent variables*. New York, NY: Wiley.
- Bunderson, J. S., & Sutcliffe, K. M. (2002). Comparing alternative conceptualizations of functional diversity in management teams: Process

- and performance effects. *Academy of Management Journal*, 45, 875–893. <https://doi.org/10.2307/3069319>
- Coffman, D. L., & MacCallum, R. C. (2005). Using parcels to convert path analysis models into latent variable models. *Multivariate Behavioral Research*, 40(2), 235–259. [https://doi.org/10.1207/s15327906mbr4002\\_4](https://doi.org/10.1207/s15327906mbr4002_4)
- D'Ippolito, M., Aloisi, M., Azicnuda, E., Silvestro, D., Giustini, M., Verni, F., ... Bivona, U. (2018). Changes in caregivers' lifestyle after severe acquired brain injury: A preliminary investigation. *Biomed Research International*, 3, 14. <https://doi.org/10.1155/2018/2824081>
- Dewan, M. C., Rattani, A., Gupta, S., Baticulon, R. E., Hung, Y.-C., Punchak, M., ... Park, K. B. (2018). Estimating the global incidence of traumatic brain injury. *Journal of Neurosurgery*, 130(4), 1080–1097. <https://doi.org/10.3171/2017.10.JNS17352>
- Dormann, C., & Zapf, D. (2004). Customer-related social stressors and burnout. *Journal of Occupational Health Psychology*, 9(1), 61–82. <https://doi.org/10.1037/1076-8998.9.1.61>
- Doser, K., & Norup, A. (2014). Family needs in the chronic phase after severe brain injury in Denmark. *Brain Injury*, 28(10), 1230–1237. <https://doi.org/10.3109/02699052.2014.915985>
- Etgar, M. (2008). A descriptive model of the consumer co-production process. *Journal of the Academy of Marketing Science*, 36(1), 97–108. <https://doi.org/10.1007/s11747-007-0061-1>
- Farnese, M. L., Fida, R., & Picoco, M. (2020). Error orientation at work: Dimensionality and relationships with errors and organizational cultural factors. *Current Psychology*, 1–20. <https://doi.org/10.1007/s12144-020-00639-x>
- Farnese, M. L., Zaghini, F., Caruso, R., Fida, R., Romagnoli, M., & Sili, A. (2019). Managing care errors in the wards: The contribution of authentic leadership and error management culture. *Leadership and Organization Development Journal*, 40(1), 17–30. <https://doi.org/10.1108/LODJ-04-2018-0152>
- Gilardi, S., Guglielmetti, C., Marsilio, M., & Sorrentino, M. (2016). Co-production in healthcare: Moving patient engagement towards a managerial approach. In *Co-production in the public sector* (pp. 77–95). Cham, Switzerland: Springer.
- Haley, W. E., Marino, V. R., Sheehan, O. C., Rhodes, J. D., Kissela, B., & Roth, D. L. (2019). Stroke survivor and family caregiver reports of caregiver engagement in stroke care. *Rehabilitation Nursing Journal*, 44(6), 302–310. <https://doi.org/10.1097/rnj.0000000000000100>
- Harman, H. H. (1976). *Modern factor analysis* (3rd ed.). Chicago, IL: University of Chicago Press.
- Hibbard, J. H., & Greene, J. (2013). What the evidence shows about patient activation: Better health outcomes and care experiences; fewer data on costs. *Health Affairs*, 32(2), 207–214. <https://doi.org/10.1377/hlthaff.2012.1061>
- Hobfoll, S. E., & (2011). Conservation of resources theory: Its implication for stress, health, and resilience. In *The Oxford handbook of stress, health, and coping* (pp. 127–147). New York, NY: Oxford university Press.
- Humphreys, A., & Grayson, K. (2008). The intersecting roles of consumer and producer: A critical perspective on co-production, co-creation and prosumption. *Sociology Compass*, 2(3), 963–980. <https://doi.org/10.1111/j.1751-9020.2008.00112.x>
- IBM Corp. (2016). *IBM SPSS statistics for windows, version 24.0*. Armonk, NY: IBM Corp.
- Kjellström, T., Norrving, B., & Shatchkute, A. (2007). Helsingborg Declaration 2006 on European stroke strategies. *Cerebrovascular Diseases*, 23(2–3), 229–241. <https://doi.org/10.1159/000097646>
- Koopmanschap, M., van Exel, N., van den Berg, B., & Brouwer, W. (2008). An overview of methods and applications to value informal care in economic evaluations of healthcare. *Pharmacoeconomics*, 26(4), 269–280. <https://doi.org/10.2165/00019053-200826040-00001>
- Koskinen, S. (1998). Quality of life 10 years after a very severe traumatic brain injury (TBI): The perspective of the injured and the closest relative. *Brain Injury*, 12(8), 631–648. <https://doi.org/10.1080/026990598122205>
- Kratz, A. L., Sander, A. M., Brickell, T. A., Lange, R. T., & Carlozzi, N. E. (2017). Traumatic brain injury caregivers: A qualitative analysis of spouse and parent perspectives on quality of life. *Neuropsychological Rehabilitation*, 8, 1–22. <https://doi.org/10.1080/09602011.2015.1051056>
- Kreutzer, J. S., Marwitz, J. H., Klyce, D. W., Schaaf, K. P. W., Sima, A. P., Welch, A. M., & Niemeier, J. P. (2018). Family needs on an inpatient brain injury rehabilitation unit: A quantitative assessment. *The Journal of Head Trauma Rehabilitation*, 33(4), 228236. <https://doi.org/10.1097/HTR.0000000000000390>
- Laitinen, P. (1993). Participation of caregivers in elderly-patient hospital care: Informal caregiver approach. *Journal of Advanced Nursing*, 18(9), 1480–1487. <https://doi.org/10.1046/j.1365-2648.1993.18091480.x>
- Laver, K., Lannin, N. A., Bragge, P., Hunter, P., Holland, A. E., Tavender, E., ... Gruen, R. (2014). Organising health care services for people with an acquired brain injury: An overview of systematic reviews and randomised controlled trials. *BMC Health Services Research*, 14(1), 397. <https://doi.org/10.1186/1472-6963-14-397>
- Lee, Y. Y., & Lin, J. L. (2010). Do patient autonomy preferences matter? Linking patient-centered care to patient-physician relationships and health outcomes. *Social Science and Medicine*, 71(10), 1811–1818. <https://doi.org/10.1016/j.socscimed.2010.08.008>
- Lusch, R. F., & Vargo, S. L. (2006). Service-dominant logic: Reactions, reflections and refinements. *Marketing Theory*, 6(3), 281–288. <https://doi.org/10.1177/1470593106066781>
- Maslach, C., S. E. Jackson, & M. P. Leiter (Eds.). (1996). *Maslach Burnout Inventory manual*. Palo Alto, CA: Consulting Psychologists Press.
- Merz, M. Y., Czerwinski, D., & Merz, M. A. (2013). Exploring the antecedents for value cocreation during healthcare service provision. *Journal of Business and Behavior Sciences*, 25(2), 152–166.
- Needham, I., Abderhalden, C., Halfens, R. J., Fischer, J. E., & Dassen, T. (2005). Non-somatic effects of patient aggression on nurses: A systematic review. *Journal of Advanced Nursing*, 49(3), 283–296. <https://doi.org/10.1111/j.1365-2648.2004.03286.x>
- Norup, A., Petersen, J., & Mortensen, E. L. (2015). Relatives of patients with severe brain injury: Growth curve analysis of anxiety and depression the first year after injury. *Brain Injury*, 29(7–8), 822–829. <https://doi.org/10.3109/02699052.2015.1016451>
- Oberholzer, M., & Müri, R. M. (2019). Neurorehabilitation of traumatic brain injury (TBI): A clinical review. *Medical Sciences*, 7(3), 47. <https://doi.org/10.3390/medsci7030047>
- Owens, J., & Cribb, A. (2012). Conflict in medical co-production: Can a stratified conception of health help? *Health Care Analysis*, 20(3), 268–280. <https://doi.org/10.1007/s10728-011-0186-8>
- Palumbo, R., & Manna, R. (2018). What if things go wrong in co-producing health services? Exploring the implementation problems of health care co-production. *Policy and Society*, 37(3), 368–385. <https://doi.org/10.1080/14494035.2018.1411872>
- Payne, A., Storbacka, K., & Frow, P. (2008). Managing the co-creation of value. *Journal of the Academy of Marketing Science*, 36(1), 83–96. <https://doi.org/10.1007/s11747-007-0070-0>
- Pindus, D. M., Mullis, R., Lim, L., Wellwood, I., Rundell, A. V., Abd Aziz, N. A., & Mant, J. (2018). Stroke survivors' and informal caregivers' experiences of primary care and community healthcare services: A systematic review and meta-ethnography. *PLoS ONE*, 13(2), e0192533.
- Plé, L., & Cáceres, R. C. (2010). Not always co-creation: Introducing interactional co-destruction of value in service-dominant logic. *Journal of Services Marketing*, 24(6), 430–437. <https://doi.org/10.1108/08876041011072546>
- Prahalad, C. K., & Ramaswamy, V. (2004). Co-creation experiences: The next practice in value creation. *Journal of Interactive Marketing*, 18(3), 5–14. <https://doi.org/10.1002/dir.20015>



- Rand, S., Malley, J., & Forder, J. (2019). Are reasons for care-giving related to carers' care-related quality of life and strain? Evidence from a survey of carers in England. *Health & Social Care in the Community*, 27(1), 151–160. <https://doi.org/10.1111/hsc.12634>
- Ranjan, K. R., & Read, S. (2016). Value co-creation: Concept and measurement. *Journal of the Academy of Marketing Science*, 44(3), 290–315. <https://doi.org/10.1007/s11747-014-0397-2>
- Realpe, A. X., Wallace, L. M., Adams, A. E., & Kidd, J. M. (2015). The development of a prototype measure of the co-production of health in routine consultations for people with long-term conditions. *Patient Education and Counseling*, 98(12), 1608–1616. <https://doi.org/10.1016/j.pec.2015.07.005>
- Sapountzi-Krepia, D., Raftopoulos, V., Sgantzios, M., Dimitriadou, A., Ntourou, I., & Sapkas, G. (2006). Informal in-hospital care in a rehabilitation setting in Greece: An estimation of the nursing staff required for substituting this care. *Disability and Rehabilitation*, 28(1), 3–11. <https://doi.org/10.1080/09638280500165070>
- Schaaf, K. P. W., Kreutzer, J. S., Danish, S. J., Pickett, T. C., Rybarczyk, B. D., & Nichols, M. G. (2013). Evaluating the needs of military and veterans' families in a polytrauma setting. *Rehabilitation Psychology*, 58(1), 106–110. <https://doi.org/10.1037/a0031693>
- Schneider, B., & Bowen, D. E. (1985). Employee and customer perceptions of service in banks: Replication and extension. *Journal of Applied Psychology*, 70(3), 423–433. <https://doi.org/10.1037/0021-9010.70.3.423>
- Sebern, M., & Riegel, B. (2009). Contributions of supportive relationships to heart failure self-care. *European Journal of Cardiovascular Nursing*, 8(2), 97–104. <https://doi.org/10.1016/j.ejcnurse.2008.07.004>
- Smith, A. M. (2013). The value co-destruction process: A customer resource perspective. *European Journal of Marketing*, 47(11/12), 1889–1909. <https://doi.org/10.1108/EJM-08-2011-0420>
- Spann, A., Vicente, J., Allard, C., Hawley, M., Spreeuwenberg, M., & de Witte, L. (2019). Challenges of combining work and unpaid care, and solutions: A scoping review. *Health & Social Care in the Community*, 28, 1–17. <https://doi.org/10.1111/hsc.12912>
- Taricco, M., De Tanti, A., Boldrini, P., & Gatta, G. (2006). National Consensus Conference. The rehabilitation management of traumatic brain injury patients during the acute phase: Criteria for referral and transfer from intensive care units to rehabilitative facilities (Modena, June 20–21, 2000). *Eura Medicophys*, 42, 73–84.
- Teunissen, G. J., Visse, M. A., & Abma, T. A. (2015). Struggling between strength and vulnerability, a patients' counter story. *Health Care Analysis*, 23(3), 288–305. <https://doi.org/10.1007/s10728-013-0254-3>
- Toffler, A. (1980). *The third wave*. New York, NY: Bantam Books (US).
- van den Berg, B., Brouwer, W., & Koopmanschap, M. (2004). Economic evaluation of informal care. An overview of methods and applications. *The European Journal of Health Economics*, 5(1), 36–45.
- Verschuere, B., Brandsen, T., & Pestoff, V. (2012). Co-production: The state of the art in research and the future agenda. *VOLUNTAS: International Journal of Voluntary and Nonprofit Organizations*, 23(4), 1083–1101. <https://doi.org/10.1007/s11266-012-9307-8>
- Visser-Meily, A., Post, M., Schepers, V., & Lindeman, E. (2005). Spouses' quality of life 1 year after stroke: Prediction at the start of clinical rehabilitation. *Cerebrovascular Diseases*, 20(6), 443–448. <https://doi.org/10.1159/000088983>
- Wood, B. L. (2012). Biopsychosocial. In L. L'Abate (Ed.), *Paradigms in theory construction* (pp. 169–186). New York, NY: Springer. <https://doi.org/10.1007/978-1-4614-0914-4>
- Zampolini, M., Corea, F., Avesani, R., Boldrini, P., De Tanti, A., ... Pistarini, C. (2013). Rehabilitation of acquired brain injuries: A multicentric prospective survey. *European Journal of Physical and Rehabilitation Medicine*, 49(3), 365–372.
- Zeithaml, V. A., & Bitner, M. J. (2000). *Service marketing: Integrating customer focus across the firm*. Boston, MA: McGraw-Hill.

**How to cite this article:** Farnese ML, Girardi G, Fida R, et al. Caregivers' engagement during in-hospital care of sABI's patients: Evaluation of informal co-production from the health providers' perspective. *Health Soc Care Community*. 2020;00:1–9. <https://doi.org/10.1111/hsc.13019>