

Impact of the lack of integrated care for older people with urinary incontinence and their family caregivers: results from a qualitative pilot study in two large areas of the Marche Region

Alessia Carsughi, Sara Santini and Giovanni Lamura

INRCA-IRCCS Istituto Nazionale di Riposo e Cura per Anziani, Centro Ricerche Economico Sociali per l'Invecchiamento, Ancona, Italy

Abstract

Objectives. Urinary incontinence (UI) may have a severe impact on older people and on their family caregivers' quality of life, especially when support services are scanty or inadequate. This study investigated the support needs and expectations of community-dwelling older people with UI and their family caregivers in the Marche Region (Central Italy).

Methods. Face-to-face semi-structured interviews were carried out to eight over-60-year-old patients with UI, four family caregivers, two representatives of the Regional Health System and two pharmacists.

Results. Findings show that the insufficient supply and low quality of continence products and the lack of integrated care services negatively affects the well-being of both older people and family caregivers.

Discussion. Integrated care services and a standardized system for the periodic assessment of sufferers and a more customized service delivery, including the possibility of choosing brand and type of products for users, may improve the current provision in this Italian Region.

Key words

- family caregivers
- integrated care services
- older people
- urinary incontinence

INTRODUCTION

Global population ageing is one of the most important socio-demographic phenomena of this epoch. Across the European Union (EU) Member States, Italy reports the highest share of people aged 65 or older, who constitute 22% of the total population [1]. In association with population ageing, an increasing number of people either suffer from multiple chronic diseases – in Europe circa 50 million of people are estimated to be in this condition, making it the first cause for morbidity [2], or die as a consequence of a chronic disease. Related annual deaths are projected to rise to 52 million by 2030 [3].

Urinary incontinence (UI) is linked to age-related multi-morbidity, and as such is becoming an ever-increasing societal problem. The International Continence Society (ICS) defines UI as an involuntary leakage of urine, which is well detectable and creates social or hygienic problems [4]. On the whole, UI affects from

3% to 23% of men and from 11% to 52% of women [5], and is more frequent among institutionalized older persons, especially if suffering from dementia and limited mobility. Its prevalence in residential settings reaches a rate of 50-80%, and UI is per se also a predictor of institutionalization and of death among institutionalized older people [6].

The levels of shame and embarrassment related to UI are higher than those caused by other widespread conditions, such as depression or cancer [7]. As such, it has a strong "stigmatizing" power [8], and may deeply affect self-esteem [9]. For example, a survey conducted in the UK shows that although 25% of women and 10% of men suffer from UI, only one in ten consults a doctor for this reason [10].

The daily management of UI-related care tasks might represent a heavy burden not only for those who suffer from it, but also for their caregivers. In Italy, indeed, as in many other Southern European countries, fami-

lies are largely involved in the daily care of older people [11], and family caregivers cover between 50% and 90% of the total (formal and informal) costs for long-term-care provision [12], often not from choice but because of a lack of appropriate public supports. The assistance of an older relative with UI can have negative consequences on the caregivers' physical, psychological, social and financial status, more than in the case of a relative without UI [13], because the UI management requires a greater amount of watchfulness and implies greater financial costs [14, 15]. Many caregivers report physical exhaustion [15], due to the lack of sleep and leisure time [15, 16] and social isolation [17], because of the difficulty in living in a dignified condition that allows them to interact with friends and other family members [18]. The highest levels of burden are experienced especially by family caregivers of older people with UI associated with cognitive impairment [19].

The availability of quality products for UI (also referred to as continence products), such as, for instance, absorbent pads, and of appropriate support services on how to use them to tackle UI-related discomforts, may play an important role in enhancing the quality of life of older people with incontinence (OPI) and of their caregivers, by reducing the stigma deriving from UI symptoms [20]. In particular, pad performance can affect one's self-confidence, self-perception and other psychological dimensions [21]. The use of hypoallergenic and absorbent products can improve the patients' and caregivers' quality of life [22], by reducing the frequency of changing pads, and preventing bedsores and rash [23], thus avoiding the negative events that most affect social contacts [24]. Ensuring a comprehensive and correct information about UI and continence products' features and usage may therefore represent a crucial strategy to enhance users' and caregivers' quality of life. So far, however, only very few national health systems (NHS) in Europe provide this kind of support and training for caregivers on a systematic basis [25].

Very few studies have focused on this issue, and even less provided detailed insights on how the whole process is carried out, for example in terms of user eligibility, assignment of reliefs, and delivery procedures. Especially in the Italian context, where health-care provision is organized at regional level (i.e. the State allocates funds to regions, which are responsible for taking decisions on how to spend them to address the different health needs of regional populations), the few studies in this field were carried out by private foundations [26] and patient federations [27].

The lack of a nationwide homogeneous, appropriate support and the above-mentioned still widespread, stigma-driven silence on UI, show how difficult the situation of Italian caregivers can be: in most cases they cannot count on a strong public and private support network, appropriate information or suitable incontinent products [28]. Long waiting times for receiving the products, administrative procedures for accessing the service, and inadequacy of aids in terms of quantity and quality worsen an already weak provision [26].

To help bridge the gap in this area, the National Institute on Health and Ageing's (INRCA) carried out a

pilot study aiming at investigating the process of allocation, delivery and distribution of continence products by the Regional Health System (RHS) of the Marche Region, and at understanding the needs and expectations of older patients with UI living in the community and of their family caregivers. In light of the above, we provide first a description of the methodology employed in the study – including the characteristics of current service provision, to clarify the context in which the survey was performed – followed by an analytical illustration of the main findings and their discussion.

MATERIALS AND METHODS

The study was carried out between January and April 2015 in the urban area of Ancona (i.e. the capital city of the Marche Region). It developed through two main phases. First, the national and regional legislation governing services for continence management and the guidelines referring to the absorbent products' delivery process were analysed. Second, experts' interviews were carried out, where "experts" were considered – following Meuser and Nagel's approach (2009) – both professionals (e.g. representatives of the Regional Health System and pharmacists) OPI and their family caregivers [29].

Sample size and inclusion criteria

In order to identify the different perspectives characterizing all main stakeholders participating in the investigated phenomenon, the sample of respondents was multifaceted and included: eight OPI; four family caregivers; two representatives of Marche's Regional Health System (RHS) administration; two local pharmacists (Table 1).

The first objective of the sampling was to identify and involve persons representative not in terms of statistical power but for the knowledge they brought. Thus, the main criteria shaping the selection of participants to the study was to identify people with knowledge of the management of IU and experience of the public service dedicated to it [30]. In light of this, the individuals best fitting with these characteristics were people aged 60 and over, who suffered from slight leakage of urine or frequent urge or who had no control. They were recruited by means of a sampling among the over-60-year-old patients reporting those symptoms admitted to the "Urology" and "Neurology" wards of INRCA Geriatric Hospital

Table 1
Sample composition

Typology of interviewed stakeholders	Number
Older patients with UI	8
Caregivers	4
Representatives of Marche's Regional Health System	1
Marche Unique Contracting Authority Service (MUCAS)	1
Pharmacists	2
Total	16

UI: Urinary incontinence.

“U. Sestilli”, located in Ancona (i.e. the capital city of the Marche Region). When older persons could not answer directly to the interview due to cognitive disability, their main family caregivers were involved in responding both as proxies and as addressees of some additional specific questions. In order to investigate and compare different conditions in which UI takes place, the sample was divided into cognitively able and impaired patients. The first group embedded three sub-groups, reflecting the main types of patients treated by the aforementioned hospital wards: women with stress-related UI; people with UI treatable through sacral neuro-modulation surgery; and people with UI due to other causes.

Four family caregivers, providing care to older people with UI (different from the eight cases above), were also recruited via the same two INRCA hospital wards.

A representative of the RHS and one of Marche's Unique Contracting Authority Services (MUCAS) were identified as expert witnesses, as they play a pivotal role in managing the process of assignment and distribution of continence products. Two pharmacists were selected from local urban areas reflecting populations with different socio-economic status (in terms of income and housing conditions), in order to detect possible differences among citizens in purchasing continence products related to this factor.

Data collection tool and analysis

The topic guide used to administer interviews was adapted to the four different typologies of subjects illustrated above, but keeping the same, basic thematic areas: type of absorbent products; the process of authorization and distribution of products; critical situations encountered; and suggestions for improvement. Informed consent was obtained from each respondent included in the study, and the protocol conformed to the ethical guidelines of the 1975 Declaration of Helsinki, as reflected in a priori approval by the Human Research Committee Institution. The administration of the qualitative interviews was covered by the approval for a larger, comprehensive and longitudinal study targeting all INRCA hospitals patients in the Marche Region, named Reportage. The latest was approved by the INRCA Ethic Committee on 17th February 2011 (Approval Communication n. SC/10/272) and the approval was applicable also to family caregivers. The interviews were carried out by a psychologist skilled in the treatment of UI-related psychological malfunctions in connection with pelvic-perineal problems, who took minutes and transcribed the most important parts of conversation verbatim.

Data gathered from patients and caregivers were organized following the framework analysis approach, i.e. through case and theme matrixes [31]. This method was used to organize and manage data through the process of summarization, resulting in a matrix output that allowed the researchers to analyse data both by cases and themes.

Through the scrutiny of the raw data, the researchers identified key issues, concepts and themes by drawing on a priori issues and questions derived from the aims and objectives of the study, as well as issues raised by

the respondents themselves and views or tales of facts recurring in the data. After that, quotes were sorted out and researchers made comparisons both within and between cases. Data were rearranged according to the appropriate part of the thematic framework to which they related, and the case/theme matrixes were designed. Finally, the charts were used to define concepts up to a second-level analysis that enabled possible causal correlations to be identified among themes emerged from the inquiry. Results concerning OPI and caregivers were reported through a narrative technique, with the support of quotations extracted by the transcriptions.

Data collected from the different subjects involved in the process (from the initial prescription to the everyday use of pads), and information from the legislative framework review, made it possible to understand how and to which extent the public care system dedicated to OPI meets their needs within their social context, and to identify existing correlations among the service characteristics and older persons' behaviours [32].

The analysis allowed the identification of the main issues and the formulation of possible solutions [33]. Given the small sample, the exploratory and piloting nature of the study and the restricted number of the analysts (i.e. 2 researchers), the interviews could be managed without the support of a qualitative software program [34].

RESULTS

Continence care service in the Marche Region: legislative background

Before reporting the findings emerging from the expert interviews, it is useful to illustrate the process through which OPI and their caregivers receive continence products in the investigated regional context. The review of national and regional legislation shows that Marche Region Health System is divided into “Large Areas” (LAs), organized into District Health Boards (DHBs). LAs are autonomous and implement services for people with UI according to the minimum level of health services guaranteed nationwide for free to all citizens by law, within the limits of public expenditure set by law 332/1999. In the Marche Region, the general practitioner (GP) or the relevant specialist prescribes the type of products considered adequate to the patient's disorder, by using specific codes identifying the aid/prosthesis. With regard to continence pads, a monthly maximum of 60 pieces per patient is currently set as the standard amount by the Marche Region (except for patients with recognized special needs, who are entitled to a higher number of aids), for a charge of 19.20 € per month (as set by the State Law with Council Resolution No. 1696/2012). The GP sends this request to the Prosthesis Office (PO), which evaluates the adequacy of certification according to the severity of the disorder, even if in this region there is not a protocol for assessing UI according to validated assessment tools. If adequate, the PO authorizes the delivery of services/products and the user can receive the absorbent aids. Otherwise, the authorization is blocked until the doctor produces a new adequate prescription. Currently, no data are available for this region on the number of days

needed for a new request to the PO by the GP and the related authorization. In this regard, it should be noted that the RHS does not allow to choose pads types, nor provides any advisory services or training on how to choose and correctly use the continence products; and there is no system in place for assessing patients' satisfaction. The purchase of the continence products by the RHS is based solely on the criterion of the lowest price offered by competing companies, and the process is not (yet) managed by the Marche Unique Contracting Authority Service (MUCAS), a body which has been recently set up to draft and launch common calls of tender for the whole Marche Region. Until this is no longer the case, each LA remains autonomous from an administrative and economic point of view, and can choose the continence products it prefers, with the only condition being that it respects the general expenditure limits fixed by law.

The perspective of older persons with UI

This pilot study involved patients from two LAs. The LA n. 2 embeds four municipalities (Ancona, Fabriano, Jesi and Senigallia) positioned in the central part of the region. The LA n. 3 includes three municipalities (Camerino, Civitanova Marche and Macerata) positioned in the central-southern part of the region. Out of the eight OPI interviewed (Table 2), three came from Macerata, a town located in the hinterland at about 50 km from Ancona, a district with a potentially different approach to the distribution and provision of services and products for UI. The major part of the sample was represented by women (6 out of 8 cases), married persons (5 out of 8) and subjects with a low educational level (6 out of 8 reported an elementary school qualification). Given the high mean age (over 78), the interviewees were not active in the labor market. The older patients interviewed reported different severity levels of UI. Very often they were not fully aware about the latter, because they had not been officially diagnosed with regard to the functional quality of their disorder, so that its consequences in terms of possible discomfort for them had not been sufficiently investigated. The first three inter-

viewees did not even remember the exact time of the onset of the condition, as initially they did not place much importance on the issue. Several women in the sample showed a sort of 'sacrificial' approach in this respect, as they were used to considering work and the care of their loved ones first, before thinking of their own needs. Therefore, they took on multiple responsibilities and tried to keep everything under control, with the result of losing sight of themselves: *I didn't have time to think about it (UI), I had to work, to take care of my grandchildren and to cook for everybody. I couldn't think of myself* (Case 2).

The older patients with mild and average UI considered it to be "natural" to have slight leakages during a task requiring effort or while laughing, thus regarding this experience to be part of a "regular" process of ageing, as reported by Case 3: *It is normal that when you age even the body becomes old*.

So, it seems to be quite common that, from the onset of the first symptoms to the first visit to a specialist, many years might pass without any evaluation of the severity of the symptom or any intervention: *I do not remember when it started, maybe several years ago, at the beginning I did not care...* (Case 4).

The interviewees decided to go to the GP or to the specialist, after the appearance of a prolapse, or because the pressure to go to the toilet became very frequent. Indeed these symptoms, in the long term, might become irreconcilable with social and working life, and might require intervention by sacral neuromodulation to reduce them. In this case, for example (Table 2, Case 6), one patient reported that she felt *enervated* as a result of the necessity of going to the toilet every five minutes. She referred that, since she started to suffer from this disorder, she had *travelled far and wide before finding an answer*, as each specialist had suggested a different solution to her problem. Clearly, her quality of life had worsened considerably and she had developed a strong form of mood disorders like anxiety and depression, for which she had to take psychopharmacological drugs, with several side effects such as gastrointestinal disorders, nausea, headaches.

Table 2
Demographic features of older patients

Case number	Age	Large Area	Gender	UI	Other diseases	M. Status	Children	Education	Occupation	Support received
1	79	LA n. 2 (AN)	F	Low	None	Widow	2	Elementary	Retired	None
2	64	LA n. 2 (AN)	F	Low	None	Married	2	Elementary	Retired	None
3	75	LA n. 3 (MC)	F	Mild	None	Single	0	Elementary	Retired	None
4	84	LA n. 2 (AN)	F	Severe	None	Married	3	No degree	Housewife	Daughter
5	88	LA n. 2 (AN)	F	Severe	Dementia	Widow	2	Elementary	Housewife	MCW
6	61	LA n. 3 (MC)	F	Severe	Mood Disorder	Married	1	High school	Retired	None
7	85	LA n. 3 (MC)	M	Severe	Dementia	Married	3	Elementary	Retired	Daughter MCW
8	94	LA n. 2 (AN)	M	Severe	None	Married	1	Elementary	Retired	Daughter MCW

UI: Urinary incontinence; AN: Ancona (Marche Region, Italy); MCN: (Marche Region, Italy).

Given their different health conditions and levels of UI severity, older patients used different absorbent products. In the case of a very severe UI, some respondents preferred adult nappy pants with fixing tapes, a product that is adopted and distributed by the RHS. In case of not frequent leakages (mild or moderate UI), users preferred rectangular pads. As for quantities, for half of the patients the number of absorbent products provided by the RHS is inadequate or insufficient, and patients suffering from severe UI have to buy additional products out of their own pocket: *I have to spend a lot of money every month to buy pads. That's incredible. I'm disgusted*, said Case 4, and *really I spend too much on buying the products I need* was Case 3's remark. The expenses borne by the interviewed users for filling this gap amounted to about 100-200 € per month. Much more expensive is the cost sustained by the older patients' families in terms of private care work (e.g. migrant care worker or private nurse), hired to provide support in everyday care delivery – including continence care – since for this, three out of five of the interviewed households spent approximately 1700-1800 € per month.

It is finally worth mentioning that there is an evident mismatch between older people's continence needs and the type of products delivered by the RHS: *These kind of pads are no use for me! I need a different model of pad! I can't go outside with these big ones!* said Case 1. This is evident in light of the fact that often patients suffering from mild and moderate leakages prefer buying more suitable products, rather than accepting those supplied by the RHS, even if free of charge, because these pads are suitable only for persons with severe UI. This is partly due to the fact that OPIs usually cannot choose and select absorbent products.

The perspective of family caregivers

Family caregivers were represented by three women and one man living nearby the cared-for person. They started caring for their elderly relatives from the very beginning of the symptom onset, and continued doing so, mostly on a daily basis, for about 5 to 6 years. The main motivations for providing assistance were love, affection and sense of duty. The interviewees often needed support for themselves, including better information on how to deal with UI management. They reported many somatic disturbances, such as crying, anger explosions and insomnia: *I often cry and feel angry* (Case 2).

Daytime tiredness is the consequence of the psychological and physical burden they experience every day. Indeed, most interviewees reported that caring for an OPI affected their own quality of life, contributing to the onset of a prevailing sense of daily sadness. A woman stated: *Yes, to stay in close contact with a sick person is emotionally conditioning, in the sense that you feel sad all the time* (Case 1), while another complained *'I am exhausted, both mentally and physically* (Case 4).

Changing pads at night is a particularly annoying discomfort, as this activity affects not only the quality of sleep, but also the quality of life during the following day: *I do not sleep well, because I have to wake up several times a night for changing pads or because my mother calls*

me and screams (Case 3). Family caregivers also complain about the lack of respite and the interruption of any social activity due to care commitments.

One of the main problems faced by the interviewed family caregivers, however, were the lack of information about the prices and characteristics of the continence products, and the lack of training on how to best apply and manage pads: *We don't know anything about the cost of the pad and its characteristics, we only know that we have to use it because that's the law... we can either accept it or not... that's it!*, said Case 2.

Three out of four caregivers received products at home, but none could choose or indicate the preferred way of delivery, nor the model of pad. Those receiving pads at home considered this delivery modality as acceptable, while the one who had to collect the products in a pharmacy defined this mode of delivery as *non-functional*.

In light of these difficulties, several suggestions were collected from among the interviewees. On the one hand, older patients suggested implementing the home distribution of continence products in the whole regional territory, and underlined the necessity of increasing the number of products supplied per month, because the current number is insufficient for a medium/severe UI level.

On the other hand, family caregivers suggested that help from public services should be increased, especially in the form of more information about continence products' features and their usage: *We need more information about UI in general, about the products to use and how to use the pads, too!*, said Case 5. All interviewees in general complained about the lack of clear eligibility criteria, and the long and difficult procedure needed to obtain the pads supply: a problem that they suggested should be tackled via a substantial simplification of the related bureaucracy.

The perspective of pharmacists, of regional representatives and of the Italian Federation of non-continent persons

In Ancona and its surroundings, the delivery of absorbent aids currently takes place through the pharmacies, where all types of continence products are available. Thus pharmacists represent strategic "expert witnesses", and can provide a more in-depth understanding of service criticalities. For this reason, two pharmacists working in two different urban areas were interviewed, reflecting socio-economically different neighbourhoods.

Pharmacists noted, in the first place, that users often buy products that are not among those covered by the RHS, because out-of-pocket purchased products provide a higher satisfaction, since patients can choose high-quality products that better fit their personal needs.

Secondly, in their opinion, the number of pads currently provided by the RHS should be increased, because this is the only measure that can really enhance users' quality of life. One pharmacist was quite favorable to the adoption of a voucher system (according to which eligible recipients would receive a voucher of a certain value, which they can spend in any pharmacy,

possibly integrating its amount with their own resources to choose the type of products they wish). The other interviewed pharmacist, however, believed it would be better not to change the current practice, thus suggesting that the current system should be kept (and amended only in terms of higher quantities of products allocated to users). Both, in any case, would prefer to maintain the 'advisor and consultant' role, a trust-based role that they have been able to build with their customers over the years.

According to the MUCAS, a possible solution for improving the current process of allocation and distribution of continence products might be found via a more effective, standardized system for assessing the amount and frequency of urinary leakages. This position is based on the observation that, currently, a wrong evaluation of the severity of the symptoms by the general practitioner can easily lead to a wrong prescription of continence aids: *What we need is not so much a different way to distribute devices, but rather a different way to assess the congruity of the product. At the beginning of the whole process, the doctor's prescription is often superficial, as he doesn't consider the severity level of UI itself, including for how long the person has been suffering from it, or what kind of UI he/she suffers from and his/her need to reach a toilet etc.*

As a consequence, within the current system in the Marche Region, it repeatedly occurs that a person with a low UI severity ends up receiving the same products as someone suffering from a far more severe UI level.

DISCUSSION

The study results are compliant with previous Italian studies highlighting the delivery process criticalities [26, 27] and the literature concerning the additional burden posed by UI-management for family caregiver [35] on different realms of life [35, 25] and in terms of social isolation [36, 18]. This study confirms that UI is often not recognized as a disorder worthy of attention, either by sufferers or by their caregivers, because both consider it as a component of the 'natural physiological process' following age-related deterioration. This behaviour may conceal the shame that characterizes UI, and confirms the 'stigmatizing' power of the condition, which may have hindered a prompt symptoms' evaluation for a timely and proper intervention [37, 38].

The study shows the interaction between psychological-biological and social factors and proves that UI can lead to the development of psychological disturbances' development, which are exacerbated by the difficulty in finding the right response.

Moreover, the study also underlines the need for a standardized and uniform system for the assessment of the patients' condition and for a customized system for assigning continence products, in order to take into consideration the possibility for users to choose the type and quality of aids according to the severity of their UI.

Furthermore, the lack of a long-term and integrated care system for the assistance of older people with UI and for the support of their family members is evident in the Marche Region. The public service is indeed limited to the free-of-charge delivery of continence products that are insufficient in number and quality. This

forces patients to purchase out-of-pocket additional and better aids, with financial consequences. Thus, the current service seems to be disrespectful of OPI's dignity, well-being and economic condition.

The observed lack of information and training services for patients and caregivers suggests, in addition, that ad hoc training opportunities on how to manage relatives with UI and support for the emotional aspects that might derive from the caring activities (i.e. anxiety, fatigue, anger) should be offered especially (but not only) at the point of discharge from hospital wards.

While the qualitative approach of this study allowed to carefully analyse the different facets of the examined issue, the investigation presents also some limitations. The first is the local coverage of the collected data: additional cross-regional research on this issue is needed in Italy, to gain a clearer picture of possibly different regional policy approaches to ensure fair and adequate assistance to OPI and their family caregivers across the country.

The second restriction is the small sample size that, albeit compliant with the qualitative nature of the research design, cannot provide an exhaustive picture of the phenomenon at national level. Nevertheless, this first study gave insights for another quantitative study in the Marche Region involving larger samples, started in March 2016, whose findings are being currently analysed.

CONCLUSION

The study results provide evidence that when integrated and tailored services for UI are missing, OPI and family caregivers can experience emotional and physical upsets and that the insufficient provision of continence product exacerbates this condition. Thus, the main suggestion arisen from the study is to consider UI as a bio-psycho-social disorder needing a multidisciplinary, integrated and holistic approach, for taking care of the entire person (e.g. environment, family and social relationships, psychological well-being, lifestyles), and not only of a single disease. Such an approach, compliant with the principle of human beings dignity and the right to high quality, timely and tailored care, could be applied to the continence care via concrete measures at Regional and National Health Systems level, and it would contribute to positively impact on the different actors involved in the delivery of services for UI. First, OPI might count on better continence products and prevent incontinence related discomforts. Second, family caregivers might reduce physical fatigue and avoid emotional stress. Furthermore, the Regional Health System might limit costs related to non-pertinent prescriptions and allocation of public resources, especially if this is achieved via a standardized assessment of the products' adequacy to users' time-sensitive needs.

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