Quality of life of carers managing incontinence in Europe

SURVEY REPORT
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1 INTRODUCTION AND THE AIM OF THE STUDY

Substantial research has been carried out on the attitudes of professional care staff in relation to incontinence care, which is often seen as a time-consuming, heavy task, preventing more positive and rewarding approaches of providing assistance to older dependent care recipients (24). These findings refer in most cases to studies carried out in institutional care settings and mainly in non-European countries, where the availability of formal care services is often less widespread than in Europe. On the whole, very little research has been carried out in Europe in the area of incontinence that has actually focused on the direct experiences and attitudes of informal carers, despite the increasing interest for home-based care provision.

EUROCARERS\(^2\) and SCA Hygiene Products, have therefore developed the qualitative research project ‘Quality of life of carers managing incontinence in Europe’ in order to start exploring the experiences of people caring for their older, incontinent family members. In particular, the study focuses on the impact exerted by incontinence care on the quality of life of adult spouses, partners, children (or in-laws) caring for community dwelling, cognitively and/or physically dependent older people (65+) living in urban areas and suffering from urinary and/or faecal incontinence on a daily basis. The research principally aims at identifying the effects to family carers from such care in emotional as well as physical terms, for a better understanding of the measures and interventions that might improve the current situation, answering to the following research questions:

- What are the specifics of incontinence care compared to other care tasks performed by informal carers?
- What specific challenges and support needs derive from it for carers providing support to the elderly with different characteristics?
- How can these carers’ needs be best met?

When incontinence symptoms affect frail, elderly people they may seriously influence not only their physical, psychosocial and social well-being but also the lives of family members/partners taking care of them, leading to carer stress and an older person’s institutionalization (18).

As for urinary incontinence (UI), it is a common condition, especially in women, and its prevalence increases with age. Different studies have shown a wide variability among UI prevalence\(^3\) rates, mainly due to differences in the sampling frame, response rates, definition used, types of UI investigated and survey methods (23).

Considering the results of the EPIC study, the largest population-bases survey that used the 2002 ICS definitions and conducted in four European countries (Germany, Italy, Sweden, UK) and in Canada to investigate the prevalence of overactive bladder (OAB), urinary incontinence (UI) and other lower urinary tract symptoms (LUTS), the prevalence of daily UI in the population over 60 living in the community is 10.4% for men and 19.3% for women (17). Prevalence figures for faecal incontinence (FI) varied considerably in studies carried out with community dwelling population

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1 Eurocarers defines a carer as a person providing unpaid care to someone with a chronic illness, disability or other long-term health or care need, outside a professional or formal framework.

2 Eurocarers, European Association Working for Carers, seeks to represent and act on behalf of all informal carers, irrespective of their age or the particular health need of the person they are caring for. It shall pursue philanthropic, educational and scientific ends with regard to the representation of carers. Among its principal aims are: Contributing to policy development at national as well as European level supported by evidence-based research; the exchange, gathering and dissemination of experience, expertise and good practice, as well as innovations http://www.eurocarers.org.

3 Prevalence is defined as the probability of experiencing a symptom or having a condition or a disease within a defined population and at a defined point in time.
aged 65 years and over, ranging from 3% to 8.7% and growing as people age (17). In a study carried out in the Netherlands with women aged 60 years and over, a prevalence range of 4.2% - 16.9% for FI was recorded (17). Considering that the level of physical or cognitive impairment present in the above studied population is not known, we should assume that the prevalence of both UI and FI is much higher than those mentioned in the frail elderly population, which is the target of our study.

1.1 An overview of the national social and health frameworks: information, support and services for (old) incontinent people

In order to contextualize the findings of the field studies, this section focuses on the framework of social and health services for old and incontinent people at national level. What support and services are available for incontinent people and their carers in each country for improving the quality of their lives?

In all countries we found services specific to incontinent people and others that also affect the management of them, even if they focused on the entire disabled elderly population. Moreover, since this study aims at understanding the impact of incontinence on informal carers’ quality of life, one section is dedicated to the support and services for carers of elderly people, where they are provided.

1.1.1 Services and support specific to incontinent people

In the four countries, incontinent people are entitled to a free supply of incontinent products according to the patients’ needs as prescribed by a GP or medical specialists (the urologist). In Sweden the district nurse or other registered nurse who has taken a specialist incontinence education course can also prescribe these aids. In each country the incontinence products are purchased following a specific procedure, based on Municipal (Sweden), Regional (Italy) or National (Slovak Republic) rules. Each country follows specific admission criteria: in Slovakia and in Sweden the number of pads is dependent on the individual’s needs and is regulated on the basis of the severity of the incontinence while in Italy the supply is not regulated on different levels of need. In the Netherlands many of these aids can also be purchased on web shops.

In Italy the quantity of support is calculated in terms of “number of incontinence products per month”: the regional law (Ministry Ordinance 27th August 1999, n. 332) allows the distribution of 120 pads or 150 absorbent pants or 150 strips or 30 elastic pants per month. All these products are interchangeable according to the users’ needs but no more than 120 items per month. On the contrary in Slovakia it is calculated in terms of “money spent for the purchase of the incontinent products”: EUR 17.47 per month for patients suffering from minor incontinence severity and EUR 58.32 per month for people suffering from major incontinence severity.

In Sweden the amount of products a person is authorized to receive is very individual and there are no limits. For example, a person may need a thinner product one day whilst another person may need 5-8 thick pads per day and also may need to have a prescription for a sheet and mattress protection and special underwear enabling protection to stay in place. The main difference between countries is in the number and quality of the guaranteed products: in Italy they are of a lesser quality than those provided in Sweden, where great attention in the purchasing process is given to factors such as quality, environmental factors and price. In this country the professional that prescribes the assistive devices must be able to assess the user’s needs, test them to ensure that the product/s are individually suited to the particular user in question, instruct and train the user and subsequently follow up and evaluate the prescribed products.

1.1.2 Accessibility to information about incontinence

In all four countries two types of websites can be found: those that give medical information about causes of incontinence and related therapy and those that aim to unite people who suffer from incontinence to achieve social visibility and improve public awareness on this topic.
In Italy, many sites address the incontinence subject by discussing it from a medical point of view, but only one association of incontinent people is on the internet, FINCO (http://www.finco.org/). This association provides information about services and support for incontinent people and their carers beyond medical treatments and organizes different types of awareness activities. In the Netherlands there are several sites providing information about incontinence and one in particular (http://www.incontinentie.net/) hopes to reduce the taboo about incontinence and expects to bring those who deal with incontinence problems closer together, discussing the social aspects of incontinence, the latest research news, media and further references. This website is owned and operated by people who themselves or their environment deal with incontinence. The daily maintenance of this site is financially supported by sponsors.

In Slovakia, there are several websites on which incontinent people and their carers can look for information and ask specialists about their particular problems. These include: http://www.inkoforum.sk/, http://www.tena.sk/profesionali/pavilon-produktov/vyhladavac-produktov/, http://www.csz.sk/dokumenty/poradna_info/poradna11.pdf, http://www.inkontinencia.sk/

The HARTMAN enterprise, which deals with the production of various medical devices including incontinent products and hygiene products in the Slovak Republic, has organized the HARTMAN TOUR for the past 5 years. This year the event will take place in May and June in 10 Slovak towns. The event is designed for senior citizens and disabled people, who are most at risk of incontinence, high blood pressure, chronic wounds, or decubitus.

In Sweden, information about incontinence is also available on a range of websites. For example, www.sinoba.se, which is a civil society organization for incontinence and bladder problems. This website offers information about urinary tract functions, the range of common symptoms and about investigations and treatment methods. Another website is www.nikola.nu, which is a network for incontinence for municipalities and health care regions hosted by the Swedish Institute for Assistive Technology. The network works with national core guidelines as well as other activities. Other more general information sites that include information about incontinence problems and how affected people can seek help can be found at www.1177 (the national health helpline) and on www.vardguiden.se (a healthcare website developed in the Stockholm region).

### 1.1.3 Support for carers of old (incontinent) people

In Italy, services specifically addressing the needs of family carers of older people are rare, and only present in some of the more advanced regions in the northern part of the country. Nevertheless, a number of laws were introduced in 2000 to promote better reconciliation between paid work and family care. Workers who provide care to a disabled family member are entitled to three paid days leave per month, so that they can assist disabled relatives (spouses, children, parents, brothers and sisters, grandparents-grandchildren, uncle/aunt-niece/nephew) (law no. 104 / 1992). No financial aid is available to unemployed carers of older people in Italy.

In the Slovak Republic, more attention is given to family carers. People facing social hardship are entitled to the nursing allowance, which is means tested and its amount in individual cases depends on the income of the person cared-for. For family carers who do not work, the government

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4 Condition is however that the assistance is continuous and exclusive, also in absence of cohabitation, as specified by Law, March 8th 2000, n.53 (article 19). Employees are entitled to three paid leave days per year in cases of serious illness afflicting a relative (spouse, children, parents, brothers and sisters, grandparents-grandchildren) (law no. 53 / 2000, "Measures to support motherhood and fatherhood, the right to care and training and the coordination of city times"). Furthermore, both public and private employees may take up to two years paid care leave (even split into shorter periods) to assist their dependent relatives, this time however not being counted for pension purposes. At the beginning the Law 53/2000 granted paid care leave for parents of disabled children only, the Law 388/2000 was amended and extended this right to also include children of disabled elderly parents.
pays obligatory social and healthcare contributions. Family carers are also entitled to 30 days holiday each calendar year for rest and 8 days for managing urgent matters. Family carers outside the labour market longer than 2 years are regarded by the authorities as vulnerable people when looking for employment and accordingly are entitled to the appropriate help. People providing care and contemporary work are entitled to flexible forms of work (as working from home, fewer working hours etc.)

Since the late 1990s in Sweden, as a result of a major government initiative called ‘Family Carer 300’ (so called because SEK 300 million were allocated to stimulate carer support initiatives in municipalities across the country) municipalities started projects which often involved a dedicated care practitioner, called a ‘family care advisor’ to work specifically with family carers and in many cases the work was directed towards family carers of older people. With the change in the Social Services Act in July 2009, municipalities were obliged to offer support to carers for the first time and funds were allocated for the first two years to help implement the law. In this country respite care services (regular short stays in dedicated respite care settings including the possibility of emergency respite care admission should a crisis occur) are offered in the vast majority of municipalities, however the range and quality still tends to vary widely across the country. Financial benefits are available to carers, however they have tended to diminish in frequency in recent years.

In the Netherlands the carers can count on an annual monetary allowance of EUR 250 euro and on the support of a case-manager who sets up a diagnosis trajectory, coordinates the care provided and informs and advises the client and carer. The carers can also call the carers’ telephone line when they have questions or need support, or when they just want to tell their story. Carers receive a response within three working days and on indication respite care services at regional and local level.
2 LITERATURE REVIEW OF EXPERIENCES AND NEEDS OF INFORMAL CARERS

The literature review of the available evidence on the subject of this study has an international focus and based on available findings in peer-reviewed journals.

The main research questions were shortened to three key words: incontinence, carer and burden. For incontinence the mesh terms urinary and faecal incontinence were used. For burden the mesh terms cost of illness, dependency, physiological and psychological stress were used.

In PUB MED a carer is defined as: person who provides care to people who need supervision or assistance in event of illness or disability. They may provide the care in the home, in a hospital, or in an institution. Although carers include trained medical, nursing, and other health personnel, the concept also refers to parents, spouses, or other family members, friends, members of the clergy, teachers, social workers, fellow patients, etc. PUB MED was searched with the key words and the mesh terms. Journals written in English from 2000 until 2010 were selected. The full text articles were available and all the abstracts were read.

Sixteen articles were sorted out. Only articles concerning informal care, burden of informal carers and care for incontinence were selected.

In three articles incontinence was defined as urinary and faecal incontinence. In the other articles urinary incontinence or incontinence were used. Little is written, in the selected articles, on the severity of the incontinence (5-8,12,13,15,16,19,20,25-30). In a European study 80% of the incontinent women were diagnosed with stress urinary incontinence. In a later stage 3 studies were added on experiences of women living with urinary incontinence (2,3 and 14).

Approximately half of the articles had a qualitative design, mostly interviews with informal carers.

This literature review focused on three research questions:

1. What is specific in informal care for incontinent family members (friend or neighbour) with regard to other areas of informal care?

Taking care of a person with urinary incontinence is burdensome. In a quantitative study The Zarit Carer Burden Interview (ZBI) was used to assess the impact of urinary incontinence on the burden of carers. The mean total ZBI score was significantly higher in the group of care recipients with incontinence than in the group with care recipients without incontinence (13). Another study shows significant differences between groups with incontinent and non-incontinent care recipients, considering the quantity of informal care given and its associated financial costs (6,20).

A study to determine the reasons for placing a dementia patient in an institution showed that the most frequent carer complaint, at the time of institutionalization, was incontinence (followed by withdrawal and non-cognitive disorders) (29).

It is the continuing nature of their partners' toileting requirements, the need for constant watchfulness that is distinct for carers when incontinence is involved (6).

Incontinence is a demeaning condition for people who experience it, because it means that person lacks self-control. For their carers, the very nature of undertaking ‘dirty work’ signifies low status and a low paid job. Urinary incontinence is not only stigmatizing for the recipient but also for the carer (5).

2. How does taking care of an incontinent family member (friend or neighbour) affect the informal carer in psychological, physical or other ways?

The impact of incontinence on carers is dependent on ‘underpinnings’, carers mention the life long love, friendship and acceptance that formed the foundation from which the carers could address the needs of the recipient (6). However, taking care of a family member with incontinence problems has a big impact on the daily life of the carer. The continuous nature of the incontinence problem evolves quickly into carer responsibility (19). Controlling incontinence, the constant need for watchfulness (even short breaks in the carers’ attentiveness can be ‘risky’) is a burden to carers (6,16).
Furthermore the embarrassment of leakage and the danger of odour can lead to decisions that can isolate the carer and the recipient within the confines of their home. Carers experience the need to manage the environment to ensure both the carer and recipient appear socially acceptable. In the process the home-space can become transformed in such a way that is difficult to accommodate visitors (5). Several studies describe the feelings of social isolation. Carers experience social isolation and minimal interaction (7) and feel it’s difficult to maintain their own social lives (6). Also there is the experience of role change; taking on responsibilities for tasks previously assumed by the recipient as a result of weakness (8). There are new tasks related to incontinence like regular prompting to pass urine and the use of incontinence aids (6). Finally a remark on carers of people with dementia. Carers experience incontinence as an extra burden when the recipient has dementia, because the recipient also has other behavioural problems (19). In several studies physical exhaustion was mentioned as a burden to carers. The constant need for watchfulness, also at night is burdensome (6,19). Sleeping issues were often related to incontinence, dementia of the recipient, but also to insomnia of the carers (5).

Other problems mentioned by carers were the lack of information on incontinence product selection and the ignorance of health professionals concerning products or other sources of help (25). The quantitative study of Gotoh supports most of the previously described experiences of carers. The ZBI comprises 22 questions related to the impact of the patient’s disabilities on the burden of carers. It evaluates various domains including health, psychological well-being, financial status, social life and the relationship of those being cared for. The differences in the scores of 20 items were significantly higher in the group of recipients with incontinence than in the group with care recipients without incontinence (13).

3. What are the needs of informal carers taking care of incontinent family members and what could support them?

The study on emotional support, physical help and health of informal carers of stroke survivors shows the results of an intervention presented to 73 informal carers. The intervention components included; the possibility of asking confidential questions and receiving answers from a nursing specialist, a support group where carers could discuss areas of interest with and receive help from other carers and a specialized nurse, educational links and a ‘tip of the month’. Significant, moderately positive relationships were found between emotional and physical support (social influences) and carers’ health. (27) Obviously this intervention support carers.

The results also highlight the importance of informal carers establishing an adequate self-care system that provides emotional support and physical help. Nurses could play a role in assessing carer health and needs and be aware of its relationship to emotional support.

A more holistic approach is needed beyond the focus of the incontinence issue alone (8). Paradigm shift is needed in the way professionals and services support and care for people with incontinence and their spouses (19).

Primary care advisers need to make the distinction between incontinence as a behavioural problem when the care recipient has dementia (19). Incontinence is seen as a dependency problem. Carers need strategies to provide the incontinent family member with the opportunity of (self) controlled excretion (16). Carers spent a lot of time on strategies for becoming ‘acceptably continent’ (5).

Apart from ageing, cognitive status and mental health status, incontinence is predictive of carer burden, these factors should be considered when developing strategies to offset carer burden (26). Carers will cope better using high quality products that are more absorbent (more expensive!) and effective in reducing physical carer interventions. These products could help prevent carers routinely changing incontinence pads during the night, to avoid wet beds (19).

A consumer guide to incontinence products is needed. Also more general information on incontinence in different languages. Professionals should be better informed on incontinence products and other sources of help (25).

Many patients don’t consider incontinence as very serious or they have a lack of knowledge about causes and treatment options. Only the presence of incontinence related complaints like an increase in severity or distress or the requirement of incontinence products was a significant predictor of help-seeking (28).

Incontinence has been relatively unexplored despite being a common problem faced by carers. It is recognized as a major carer burden, associated with considerable costs and a predictor of institutional placement. Taking care of a family member with incontinence problems has a major impact on the daily life of the carer. It can affect health, psychological well-being, financial status,
social life and the relationship of those being cared for. A more holistic approach is needed beyond the focus of the incontinence issue alone. Nurses could play a role in assessing carer health and needs and be aware of its relationship on emotional support. High quality products, accessible information on incontinence and incontinence products is essential for self-management.
3. THE QUALITATIVE STUDY

3.1 Methodology

3.1.1 Sampling and recruitment

General inclusion criteria
As for the general inclusion criteria, the participants consist of women/men (aged 18+) primary family carers of an incontinent parent, parent-in-law or spouse/partner (aged 65+) who is also cognitively and/or physically disabled, living at home in urban centres, and requiring daily toilet assistance due to their urinary and/or faecal incontinence. Both female and male informal carers were searched for inclusion in the sample. Additional requirements included gathering 16 interviews per country, at least 2 carers of cognitively impaired cared for persons and at least 2 husbands/male partners and 2 sons or in-laws.

Definitions used for sample selection

Urinary and faecal incontinence: according to the 2002 ICS (International Continence Society) definition, urinary and faecal incontinence are complaints of any involuntary leakage of urine or faeces (1). For the purpose of our study, focusing on ‘heavy’ caring situations, the frequency of incontinence episodes considered for inclusion in the sample is ‘at least once a day’ and the older person needs substantial help for intimate hygiene (e.g. cleaning, changing pads, toilet visits). Older persons using catheters or colostomy bags are excluded from the sample.

Family carers considered in the study: The interviewee is the family member who regularly helps the older person with intimate hygiene due to his/her incontinence problems, directly carrying out at least some of the related tasks, daily or very frequently during the week.

Cognitive impairment: screened by the presence of a doctor diagnosis for dementia or other diseases affecting cognitive abilities or by the use of drugs for dementia or similar diseases.

Physical disability: screened by the cared for person being dependent in walking, or in other terms, needing some help for moving around or using walking aids.

Recruitment channels
Recruiting study participants was performed using a wide range of channels including: home care organizations, GP, hospital wards, list of previously interviewed carers, associations of family carers, voluntary associations, snowballing, etc. Strong emphasis was put on voluntariness and confidentiality of participation.

In the Netherlands the informal carers were recruited mainly via organizations for different types of home care, while in Sweden they were recruited via urology departments of university hospitals with the collaboration of nurses working within home nursing care in the same municipality. This affected the composition of the Swedish sample, which included very sick people with high levels of physical impairment.

In Italy and in the Slovak Republic, beyond the social and health organizations, the researchers used different recruitment channels: information from municipalities, snowballing and list of previous studies. In Italy there were no male carers found for the study. In this country it is very likely for men with a family member needing frequent support with intimate hygiene to delegate these tasks to other female family members (sisters, wives, mothers) or to hire a migrant worker who carries out such tasks. This is a typical strategy adopted in Italy (9,10,11)

Ethical considerations
The ethical approval was sought in three countries of the four: This was not a requirement in the Netherlands for the study to proceed. The Slovak Republic applied for ethical approval in July and received it in September, Italy applied for it at the end of September and obtained it one month...
later. In Sweden the ethical approval was a lengthy procedure, because it had to undergo assessment at the teaching hospital first before it could be sent to the formal ethics committee for consideration. Sweden obtained ethical approval in the middle of December and the committee required that informed consent was secured from the cared for persons prior to obtaining consent from their family carer.

Informed consent was gained from the potential participants. They were approached to take part in the study and received an information letter and signed a consent form. With the participants’ permission their interviews were recorded and the interview transcripts were written out in full.

3.1.2 Data collection

This is a qualitative face-to-face interview study carried out between September and January 2011 in four countries, each representing a different macro-area of the European continent: Southern Europe (Italy, Italian National Research Centre on Aging, acting as coordinating centre), Eastern Europe (Slovakia, Institute for Labour and Family Research), Scandinavia (Sweden, The Swedish National Family Care Competence Centre) and Western Europe (The Netherlands, Vilans) (see Annex 1 for participants’ details). All the research centres participating in this project are affiliated to EUROCARERS.

The informal carers were contacted mainly by phone in order to check whether they matched the inclusion criteria. After the carers showed their willingness to talk about the topic of the study, data was gathered using problem-centred interviews. A total of 48 interviews were carried out at the respondents’ place of residence, or elsewhere if requested by the person being interviewed.

The problem-centred interview is a methodological tool that aims at reconciling deductive and inductive research methods, thus allowing researchers to utilise a number of interviewing techniques in one interview, beginning with a narrative approach (introductory question), then a thematic interview (ad-hoc questions) and finishing with a collection of ‘socio-statistical information’ at the end (questionnaire). Therefore, in line with Witzel’s assertions (31), for each interview the researcher had:

- A short questionnaire to gather data on the social characteristics of the interviewee;
- Guidelines or ‘a supportive device to reinforce the interviewer's memory on the topics of research and provide a framework of orientation to ensure comparability of interviews’ (31);
- Tape recorder;
- Post-scripts to accompany tape recording.

Inside the Topic-Guide based on the problem-centred interview, some quick-scan questions were added for gathering demographic data and information from the Barthel Index and Cope Index (adapted to incontinence care). The use of quantitative data allowed interviewers to check the content of qualitative information and helped to better understand the amount of support and services used by the carers and the level of disability of the old people. Finally it was possible to better understand the whole care situation. The SPSS programme was used for analysing quantitative data.

The topic-guide was based on the information from the international literature review and on the partners’ expertise. The most relevant aspects of the object of the study are included: caring history, daily routine of incontinence care, impact feelings and experiences in caring for an incontinent older family member, formal and informal support received in caring. The main focus of the interview is on the experience of incontinence from the carer’s perspective.

The interview guide, initially written in English, translated into national languages and re-translated into English for assuring the equivalence between national versions, was pilot tested with at least one carer per country to check both the acceptability of its contents and the amount of questions that can reasonably be asked in a one and a half hour period. Based on the results of the pilot interviews the guide of topics were revised.
3.1.3 Data analysis

In each country the interviews were audio-recorded and transcribed literally. The analysis was supported by MAXQDA programme for classifying, connecting and combining data.

Data was analysed through the Qualitative Content Analysis method that helped to read each sentence to search for the answers to the research questions. As demanded by Mayring (22) the researchers defined the units of analysis and the code unit, from the smallest (the word) to the biggest (the whole interview). Qualitative content analysis is defined “as an approach of empirical, methodological controlled analysis of texts within their context of communication, following content analytical rules and step-by-step models without rash quantification”. (21) The Mayring method is based on structuring with regard to content, filtering specific topics, contents and aspects out of the material and summarizing it. Each extracted fragment of text is named by categories, and (as far as necessary) sub categories (21). Code Words were arranged by subject, and were organized in a code-tree. Texts were read again and fragments were still attached to codes. In other words, all textual data has been read and then variables were labelled and named “categories” (4).

A system of main categories common to all countries was built on the basis of the Topic-Guide (so topics such as medical history, problems, impact and daily routine) and other two further levels with subcategories were built after the whole material was read, following a high level of specific data based on the national features of each country.

3.1.4 Description of carer’s profile

In all countries women are prevalent: 100% in Italy, 70% in Slovakia, 80% in Sweden and 67% in the Netherlands.

The average age is lower in Italy (57 years) than in the other countries: Slovakia 59, the Netherlands 67 and Sweden has the highest average age with 78 years. This feature explains the employment status of Swedish carers, who are all retired.

Italy has the greatest percentage of carers working full-time (31%) while the Netherlands has the greatest percentage of people working part-time (44%). In the Slovak Republic full-time, part-time, self-employed are quite equally distributed with almost half of the carers of retirement age (47%).

The prevalent type of relationship between carer and recipient is a son/daughter relationship and in particular daughters take care of elderly parents in all countries (63%), while sons as carers are few (3 in Slovakia and 1 in the Netherlands). 48% of the sample are married to the recipient, with a prevalence of wives who care for husbands (38%). In Italy there is only one wife.

Most of the carers have a medium-low level of education.

3.1.5 Description of cared for person’s profile

Some information about the cared for person’s profile was gathered: the gender, age, memory and/or cognitive problems.

With the exception of Sweden (11%), in all countries the female cared for people are predominant: 77% in Italy, 65% in Slovakia and 56% in the Netherlands.

Italy and Sweden have the highest average age among the countries (84 years), followed by Slovakia (77) and the Netherlands (80).

The majority of cared for people had severe cognitive problems, in particular 62% in Italy, 53% in Slovakia, 22% in Sweden and 89% in The Netherlands.
3.2 Findings: Comparison of the results of the study arising from the four countries

3.2.1 Medical care needs of cared for people

In all four countries the most interviewed carers managed incontinence of people who were cognitively impaired due to dementia. Besides this ailment there were cases of stroke, transient or ischemic attacks, of T.I.A., hearth failure, hip fracture, physical impairment (caused by stroke), muscle disease, rheumatic arthritis or ageing. Some patients had gradually increasing care needs, due to multiple reasons. As a consequence of the abovementioned diseases, most of them are unable to perform ADL.

In Sweden the interviews took place with patients who were seriously ill and had a range of long-standing chronic conditions. The participants in the interviews started caring for their respective spouses/partner/mother due to the onset of chronic illnesses. Namely stroke, neurological illness, prostate cancer, bladder cancer, penile cancer and dementia.

“The problem grows little by little and I’m there all the time, so there is no respite. I try to help him the best I can.” (Sweden)

“Caring started three years ago, in December 2007, after being affected by the stroke. He felt bad, dragging his leg. Then he went to the hospital and through the entire hospital care-path spending 3 months at the Villa Adria rehabilitation centre… and now here he is…” (Italy)

“Well I began to care for him after his first leg was amputated, and that was ten years ago.” (Slovak Republic)

3.2.2 Reasons for taking over care

The carer’s reasons for caring are mostly related to the kind of impairment and to their relative’s level of care need. However, other factors do affect the decision of caring, for instance: living close to the recipient, being a single child and the carer’s feelings towards the recipient. The choice of caring for an old family member is usually due to a combination of the aforementioned factors.

We found four main reasons for caring among the interviewees: sense of duty, gender scheme, sense of reciprocity and love. Among all, caring seems to be more motivated by the last two reasons: love and sense of reciprocity.

“We don’t let each other down, we promised that when we got married.” (The Netherlands)

In Italy the real reason for caring was often understood during the conversation through the carer’s non-verbal expressions. This is the case in woman who appear very angry due to their husband’s ill health, but also to the poor relationship between them. She doesn’t care for him because of love, but because of a sense of duty and she talks about him as a bad, unfeeling and selfish person, even before he had a stroke, three years ago. Also in this country two women decided to care for their elderly family member according to a gender scheme, that is when their elderly parent got worst and offered for him to live with them, whereas their brothers did not even consider such an option. Although this behaviour cannot be considered as a general rule, in Italy daughters rather than sons do feel particularly personally responsible or committed to their parent’s care, according to a cultural belief that female family members are more skilled or inclined to care than male family members (9). Other carers care for the elderly people as they have a special love relationship with them.

In Slovakia certain factors lead to taking care of an elderly relative with incontinence, namely preventing from placement of the relative with incontinence in a social care institution. There were also other reasons, not so frequent, and they were reported as “other reasons next to major reasons”, indicating that several reasons have influenced a decision to take care of a relative
with incontinence. Some carers took over the care in a natural way:

“My husband was already in a wheelchair when we met [...] I was aware of what was expected of me even before the wedding”. In another case a carer added that it was his own decision “… I am going to take care of her as long as I can.” (Slovak Republic)

In one case, a sense of duty, expressed as the reason, was not a natural decision, but a result of the pressure of circumstances as the carer reported that “she is a member of the family”, but the interview revealed other circumstances that forced her to become a carer. Financial costs as a reason, along with emotional reason were also observed.

For the majority of carers in Sweden, helping to care for their relative was seen to be a natural extension of their relationship. For the spousal carers, they perceived their caring role to be a fundamental part of their marital relationship. However, for one carer who was a long-term partner, she primarily took on board her caring role out of a sense of duty. She explained that her partner did not have any other relative living close by to care for him. Also, she was highly dissatisfied with the lack of quality of the respite care services they received so that she felt that there was no other alternative. In one case of a daughter who took care of her mother, she explained that she had always had a close relationship with her mother. Thus, it felt entirely natural for the daughter to help her mother so that she could stay at home as the daughter lived close by.

“She has used my bath until very recently. She was very clear that I washed her everywhere but that she managed her private parts herself. It’s the last thing in some ways. I’m aware that I’ll do that if necessary, but then I’ve crossed a limit. Not because I think it’s awkward but because I’m taking something away from her.” (Sweden)

Several carers mentioned the importance of enabling their relatives to stay at home as their relative had not previously enjoyed their short-term stay at a respite care setting or rehabilitation unit.

Some informal carers in the Netherlands reported a sudden change in their loved one’s health status, which made the care necessary. They felt they had no choice. Others said the care became gradually more and it felt natural. Additional aspects that were mentioned were the fact that the recipients preferred the care from their own partner or child and the fact that informal carers wanted to prevent admission to a residential or nursing home.

Two informal carers cared for their loved ones at home because they would rather be independent from formal health care. One informal carer found it completely natural to take care of a parent.

In Italy more than half of the interviewed people (seven cases) started caring three to ten years ago often due to a cognitive impairment of the recipient, and six people started less than three years ago, of which two very recently, a few months before the interview. Most recipients (nine cases) started needing care gradually, as a consequence of being affected by slowly developing cognitive symptoms. The others needed care suddenly after an acute episode of stroke, T.I.A, heart attack or heart failure.

Informal carers in Slovakia have been taking care of their relatives with incontinence for different lengths of time. The shortest period of time listed in the Slovak group was four months, while the longest period of time was eleven years.

For several carers in Sweden, as the onset of their relatives’ illness was insidious, it was difficult for them to specify the exact year when they began helping to care for their relative. For the majority of carers, the process was gradual and ranged between approximately two to thirteen years. Even for the stroke carers, the onset of caring tended to be gradual as their relative also had other co-existing chronic illnesses, such as prostate cancer. For the majority of cared for persons, incontinence problems began approximately two years ago and in one case over a longer period of six years.

“The problem grows little by little and I’m there all the way, so there’s no respite just because he’s poorly. I don’t care any less because of this, other than that I’m with him and I try to help him the best I can.” (Sweden)
The informal carers interviewed in the Netherlands took care of their partner or parent for two to nine years. Most recipients became incontinent between one and three years ago. Suddenly, for example after a stroke, or gradually, for example due to rheumatic arthritis.

“My mother always stated that she wanted to live in her own house for as long as possible.” (The Netherlands)

3.2.3 Daily routine and problems encountered in incontinence care

Daily routine

The persons interviewed were asked to explain and exemplify their care activities around the clock and give concrete examples and stories as to their daily routines with incontinence care and other caring tasks. This approach was expected to allow the carers to ‘open up’ and feel at ease while telling about their caring experiences for an incontinent person, to highlight the problems they usually experience, how they try to overcome them, and to identify what would be useful to make things easier in their daily lives.

In all countries it was not very simple for carers to distinguish incontinence care tasks from other forms of help they provide to the loved one. Generally, the effort required from the carer for toileting the incontinent person, depends on the type, level and frequency of leakages and on the general health conditions of the person cared for.

The most reported daily routine activity of carers for family members with incontinence is cleaning and washing them, clothes and bed sheets. The carers do the cleaning and changing of incontinence products at different places and with different frequency, depending on the recipient’s mobility, whether the client can walk to the toilet/bathroom or can get up from bed by himself or with the carer’s assistance. When the recipients can walk to the bathroom on their own, they need someone there to remind them what they need to do. Some carers position their clients on the toilet several times a day, or they use preventive methods to save from cleaning (they try to control the stools at least).

Carers have different timing and time intervals for performing activities. For some of them the day begins early in the morning, for others much later. Those carers, who must perform some activities around the recipient before going to work, have indicated an early start to the day.

“Well, I get up at 5 or 5.30 a. m. and I start immediately. I have to change diapers, maybe even all bed linen, which is sometimes three times a day. Then breakfast, washing and cleaning etc.” (Slovak Republic)

“I need to clean his bottom and change his pad. He’s made clean in the morning by them (home care nursing) and in the evening. But things can happen during the day and so then I wash him down, dry him and put on a clean diaper. Things can happen at night too, so it’s round the clock.” (Sweden)

Several carers encouraged their relatives to do as much as possible themselves in order to maintain their autonomy and many of them also provide help during the night. Beyond the activities related to the intimate hygiene and to the changing of pads, the carers help with feeding, dressing, moving and doing all activities of daily living they are not able to do by themselves. Some carers often deal with bureaucratic aspects in order to achieve care allowances and other support and all are used to doing household tasks, administration and activities around the house, ordering incontinence products and arranging home care.

“I’ve less rest now than when I worked. I’m a bit overtired, I cry so easily but I don’t tell anybody that I’m sad.” (Sweden)

Managing incontinence influences the daily organization of the carer a lot, because he/she has to schedule all the other tasks on the basis of pad changes. The main consequence is the lack of freedom. The quantitative data analysis confirms that the majority of carers provide incontinence and physical care on a daily basis (75%) and that almost all provide intimate hygiene (95%).
Three kinds of problems related to incontinence care were found: physical and emotional, practical and behavioural aspects of the recipient.

**Physical and emotional problems**
The problems included mostly physical issues, resulting from exhausting lifting of the recipient, such as painful joints, spine, arms etc.: “My hands and back hurt”. Some carers indicated back problems. Back pain, tendinitis and tiredness are very common within the interviewed sample: they are the first consequences of the carers’ physical efforts to move disabled old people. Emotional issues often accompany physical problems: back pain occurs with a state of anxiety and widespread tension and strain.

In Italy all carers reported back pain and physical problems related to the physical efforts of changing pads and moving their elderly relatives. Some of them suffered from torn tendons and other ones also from urinary leakage due to their relatives’ heavy body weight. The carers’ bad physical condition also depended on their lack of rest. Feelings of exhaustion were a common theme of the Swedish data, largely as a result of persistent sleep deprivation and significant caring activities over time.

Physical problems were not reported very frequently in the Netherlands. One informal carer had sleeping problems because her husband visited the toilet frequently at night. Informal carers also mentioned that caring could be physically exhausting, for instance when helping their partner or relative to bed.

**Practical problems**
Another group of problems are practical problems: in Italy the interviewees reported the urine or faeces bad smell, the poor quality of some incontinence products and their cost. On the other hand, if the carers are not disgusted by the smell, they regret if the cared for ones are ashamed of their own leakages. For one carer it was difficult to help her mother to the bidet, which is not able to kneel down anymore. She prefers to accompany her all the time to the bathroom to prevent her from smelling and feeling uncomfortable.

“The incontinence is the worst aspect of caring […] Incontinence is horrible, very bad both for her and for us, because there are some intimate aspects… I’m used to the smell now… at first it was revolting. I was almost throwing up, now I’m used to it and I can handle it better.” (Italy)

Many carers in this country reported they did not use the right or most appropriate incontinence products when the incontinence problems started, particularly due to their lack of knowledge and experience. Some of them did spend time and efforts searching for the absorbent product that best suited their relative’s needs: hypo allergenic products in cases of clients with sensitive skin, or absorbing pant (pull ups), which seemed to be preferred by older people with some partially remaining cognitive abilities.

“Caring for an incontinent person is an important skill which, unfortunately, no one teaches you […] how to cut the bottom absorbent pad that you put double or to fold the edges from the inside, otherwise the urine escapes. I mean there are so many trivial things, which were not told, and I’m upset with the health operator. I mean: “why isn’t there anyone explaining this to us?” (Italy)

Practical problems mostly had to do with the type, quality and delivery of incontinence products or with help from others. Protective pants, briefs, belted briefs and (under) pads were the most used products. Some materials did not prevent leakage, were torn apart easily or were not delivered on time in some cases.

Male urinals, commodes, bath chair, shower chair, armrest on the toilet, canes, walking frames, lifting hoist and ceiling lifts were also considered as helpful for daily living across the countries.

Some informal carers were not satisfied with the home care organisation and would like to receive more or better care. Or they would like to receive care from the same person every day.

It was also said that they would like to receive (more) help from family or support from formal carers. They were too tired to do everything alone or too busy to do everything they felt they should
be doing.

**Behavioural problems**

Some carers experienced most problems in case of the recipient suffering from dementia and behavioural problems, particularly during the onset of the disease, since their relatives did not accept using pads. One carer told the interviewer that her mother did not accept wearing pads and the carer’s efforts were aimed at preventing her from tearing the pads into bits or from hiding them.

“*When the elderly person starts to accept incontinence, it is easier to care for them.*” (Italy)

The interviewers encountered a variety of situations where carers had to deal with different types of behavioural problems, or a combination of these types:

- Wandering in or outside the home environment (6%)
- Difficulty with normal conversation (54%)
- Upsetting behaviour (42%)

Cognitive diseases are quite widespread among the whole sample and across countries where the majority had some type of behavioural problems. For more than half of the whole sample (54%) cognitive impairment concerns the speech area and for 42% concerns upsetting behaviour.

Some elderly people want to go to the bathroom alone risking falling down even if the carers would rather prefer to go with them. So it is difficult for these individuals to be listened to and obeyed. Changing pads and cleaning the elderly relatives becomes more difficult in cases where they are not cooperative due to their disability: their bodies are heavy and hard to move.

“*I’ve tried so many [incontinence] products. When I finally had something that worked, several months had past.*” (The Netherlands)

Carers in Sweden recounted their experiences regarding their caring situation as a whole rather than focusing on different specific caring tasks such as incontinence care. For example, a dementia carer explained that she found it difficult that her husband was nearly always tired and often felt the need to go and lie down during the day. She realised it was part of his illness, yet she explained that it was not an easy situation to manage.

In order to ascertain their experiences of helping their relative with incontinence care, the interviewer often repeatedly asked follow-up questions to help the participant carer to focus more specifically on aspects relating to incontinence care. A spousal carer who gave direct ‘hands on’ help with incontinence care, (which involved cleaning up after an accident, washing and drying the affected areas, re-dressing and changing pads) did not consider it was unduly problematic. She accepted that the incontinence problems were a result of her spouse’s illness and considered that it was ‘part and parcel’ of her caring activities such that she explained that she tried to make the best of it and ‘get on with it’.

As all the spousal/partner carers helped their relative at night often with toileting and intimate hygiene or due to pain, their sleep was regularly disturbed. In three cases the carers admitted to being extremely fatigued and physically exhausted which they also recognised made them emotionally fragile. They all openly wept during parts of their interview as they recounted their situation.

Other problems outside these three categories were that some people cared for needed a lot of personal attention or needed constant watchfulness. One person cared for drank less in an attempt to prevent incontinence accidents at night.

All of the carers explained either directly or indirectly during their respective interviews that they needed to be ‘on hand’ should anything occur. Thus, they were constantly on guard and were vigilant of their relative’s overall health status on a daily basis. They were all the primary carers so that even though several had home help services, they still felt that they had the overall responsibility for their relative. In practice, this meant that they needed to be constantly alert to their relative’s needs and situation, which fluctuated from day to day.
This could lead to very unpleasant situations, with people staying in the bathroom naked or lying in a wetted bed. All these problems were caused by cognitive problems, physical problems or a frequent and strong need to void and in one case by the use of diuretics.

Another problem was that some people cared for didn’t cooperate. They resisted help or advice from both informal and formal carers in various situations, incontinence-related and with other types of care.

3.2.4 Impact of care on carer’s life

The caring tasks have a general impact on different spheres of life: family relationship and relationship with the elderly person, social life, finances, wellbeing health and emotions.

*Relationship with the old person*

Many carers reported the actual relationship with their elderly parents had changed a lot, as it was turned upside down. In the past the parents used to help the main carers whereas now they are those needing care and support: for this reason children become parents and parents become children. Such a role change causes suffering and embarrassment to carers.

“We have double roles, and they overlap each other in a wrong way. Sometimes, I should still like to have my strong mother who could support me, because I also need help in one way or another.” (Sweden)

*Family relationships*

The main carer has to deal with family relationships and to mediate in the relationships between her parents, upset by the disease. As often happens within families, the middle-aged women struggles to find a new balance. Even if carers’ families feel more united in the common effort of caring for the loved one, in the majority of cases the presence of a disabled older person, the tiredness and the lack of leisure, create tension and nervousness often degenerating into an argument. In addition to this, some female carers are also mothers, who reported a feeling of neglect of their own children due to caring for their parents.

“You always have to stay with her. My husband and I can not go out together anymore.” (Italy)

In Italy some carers’ family relationships were strengthened by caring. The interviews show a difference between carer’s daughters and sons as the first ones are involved in managing the incontinence, the second are not.

In Sweden however the majority of carers did not express direct changes in family relationships as a result of their caring responsibilities.

*Social life*

Caring has changed a lot in many main carers’ social lives: caring is very challenging and the main problem is the lack of freedom to go out, meet friends or travel. Moreover they often don’t have any physical and emotional resources left to think to go out or to actually do it. Their social life has changed since taking up care of a close relative with incontinence, actually stopping some social activities altogether.

24-hour care for a person with incontinence is physically and emotionally demanding, often resulting in few opportunities to leave the house/flat, less socializing, sometimes called “being trapped at home”. A majority of carers reported that they did not regard care as being trapped at home, on the other hand they admitted they were restricted.

“...sometimes I think that if this hadn’t happened, life would be different, we could go out for a walk, or visit friends, or travel. This situation restricts us a little bit, unfortunately, that’s it, and it will not be different, but I shall stand up again and continue, there is nothing to speculate about (laughing)” (Slovakia)

“So we cannot go anywhere… we have literally not been anywhere together” (Slovak Republic)

All of the carers in Sweden explained that they were to all intents and purposes largely tied to the home because they were the main carers. The majority of carers expressed that they could leave
their relative for an hour or two at the most to run errands but they did not feel comfortable leaving their relatives for longer periods of time. For the majority of carers, being restricted to the home was largely a result of their relative's illness rather than as a direct result of their relative's incontinence problems 'per se'.

“Well, I feel that I have less freedom… but I can’t really blame that on the incontinence other than that it’s his overall illness. It’s nothing to do with the weeing. It’s everything together.” (Sweden)

Financial situation and work
In Italy financial carers experience financial difficulties, both directly and indirectly. They are direct if they are the result of incontinence, when the elderly person does not receive the free supply of diapers by the health service or when the pads from the Health Service are of poor quality or not enough in quantity terms. In these cases, they have been forced to buy additional or better ones.

“Financial hardship, as the provided pads are not enough. A pack of pads costs EUR 28-30. The anti-allergic ones are fine as she got some irritation from the other ones. The brand is (omissis) with three absorbency levels (the son in law speaking), because those with only two levels are not strong enough. With those it is fine, they do not break, they are made of a special paper material, which does not irritate the skin. We alternate them with the free-of-charge ones.” (Italy).

The financial consequences are indirect when carers neglect their jobs due to their caring commitments. For some working carers it was very difficult to reconcile work and care and experienced some financial consequences. Only in a few cases the combination of work and caring commitments altered.

In the Netherlands some informal carers mentioned expensive aids they had bought for their partner or relative, such as special cushions to prevent bedsores. Others said that the financial administration regarding the formal care was very time consuming and almost too complicated to handle.

Well-being and health
It was clear from interviews with several carers that they generally accepted their situation as they had a strong desire to help care for their relative so that s/he could remain at home. Overall, they expressed contentment with their caring situation.

Several carers expressed that their responsibility and concern for their relative meant that they always put their partner’s health first. That’s to say that they denied going to the doctor themselves even if they really needed to do so.

Feelings and experiences
In all countries negative, positive and ambivalent feelings related to caring were found. Negative feelings concern sense of oppression, pain, resignation, desperation and anger. Some carers feel oppressed by their daily heavy caring task as well as by sadness for the elderly person’s situation. Many carers are anxious and concerned about the future. Several carers get angry because of their lack of freedom as they are not able to go away, to enjoy some spare time for their own interests.

“Caring is certainly very hard and difficult. One has to adapt to so many things, you have to swallow and bear a lot. However when in the future they won’t be there any more you can not blame yourself about anything, you’re at peace with yourself and you repay yourself for all the sacrifices you’ve had to make.” (Italy)

“Well, you can go anywhere in a diaper. Anyway, we don’t go out for long, and even if we do, we don’t stay out long.” (Slovak Republic)

Disability is these carers’ greatest problem rather than incontinence that is perceived more as a consequence. Resignation, sadness and fear of not being able to manage the older person also occur.

“I’m like a little rubber band with a weak spot, tears come over and over again nowadays.” (The Netherlands)
However there are positive feelings as well. Many carers feel good when they spend time with their older relatives. They feel love and affection and they want to care for and it was their own choice. A daughter feels fine, as she won't be guilty when her mother dies.

“A beautiful thing, a nice experience, a warm welcome, feeling I love her a lot but also that she loves me a lot. So the experience is mostly related to the particular sphere of love”.

“Remember how much you loved her when she was healthy and remember that love multiplies while you are caring for her as it is such a great gift to be able to volunteer for a woman you love and who loves you.” (Italy)

“Just the expression of her face is rewarding for me, she looks at me and is happy how I managed it all.” (Slovak Republic)

“I am so happy he is here (smiling). That I am not alone.” (Slovak Republic)

Some informal carers found it difficult to name positive aspects of caring, others really focussed on these positive aspects and were glad to help their loved one. And they were glad to have them around. They didn’t want to complain, but wanted to approach the situation positively.

Also ambivalent feelings can occur: One feels a mix of satisfaction and anger. One carer is morally gratified but also nervous and exasperated by caring.

“Every carer has had such thoughts. It comes to us all at some time. He/she just says I am fed up with it, yes, but......so far, it has always helped me and my wife as well, the relationship that we have, we deal with all problems together, we make coffee and sit together at the table when my mum goes to bed, and we talk about everything and always find a solution. And when we get up in the morning we are glad that mum is still here.” (Slovak Republic)

Partners as carers felt their love relation had turned into a carer-client relationship or a parent-child relationship. Most people cared for with dementia did not show their love anymore or didn’t seem to bother about their carers’ well-being and one person with dementia became very aggressive.

However, a few carers found a special way to still connect with their husbands and wives by hugging, talking and making eye contact and two husbands still felt really proud of their beautiful wives.

Carers of parents said their relationship had automatically changed or even had to change before they were able to provide this type of care.

Another aspect of the change in relationship was the fact that the person cared for always came in first place. Carers who went out to do things for themselves felt guilty about that.

In the Netherlands a few carers sometimes wished they could give up caring, because they felt overburdened. However, they realised that in that case, their loved one would have to move to a residential or nursing home and all informal carers resisted this. They did not think the quality of care in nursing homes was better than the care they provided at home or had bad experiences from temporary admissions in the past. Some mentioned conditions in which case an admission would be inevitable, like faecal incontinence or prosopagnosia (not being able to recognize people). Others stated that there were still enough reasons to keep caring: a feeling of belonging together, or enough help from others to be able to hold on. Still others were uncertain about holding on in the near future. Despite this uncertainty, most carers were satisfied with the care they provided, or said they just tried their best.

Feelings and experiences related to incontinence.

In most interviews it was not easy for the interviewed carers to specifically reflect on their personal feelings related specifically to incontinence, which is perceived as part of the complex situation linked to disability.

There are various stages of the main carer’s acceptance path of an illness affecting both the sensory experiences, such as tolerating the new bad smells, as well as the emotional experiences, such as the displeasure of seeing their loved one not being self-sufficient any more.

The onset of the disease, in particular, is also the most difficult moment for the carer, who must work out what is happening, accept the new condition and organise the daily life differently from
what was previously the case.

Some skilled carers manage the incontinence as well as any other tasks related to disability. They are aware that someone must do it and they are the only ones able to do it. Others however perceive incontinence as the main problem of caring. For some the relative’s incontinence represents the most heavy aspect of caring, and a considerable psychological stress as it concerns the sphere of intimacy embarrassing both the incontinent persons as well their carers. According to most of them an incontinent person requires a lot of attention all day long. They often have to change the incontinent people’s pads, take them to the bathroom and so they cannot do anything else. Some carers are not even able to leave when pads need changing, so their entire day is affected by this inflexible part of the day.

“I don’t see a great difference between incontinence care and other tasks, I have to do it and it is not a problem” (Italy)

“But you get used to it. ‘You can’t do it’ someone said to me, but the things you have to do you manage. But not everything!” (Sweden)

“It is certainly a lot of responsibility. It is a lot of responsibility and it’s a must because I cannot leave her just like that. Anyway, it’s something I think about all the time. If she’s wet, I leave everything and go and change her diaper straight away” (Slovak Republic)

As outlined above, carers were really unable to dissect their specific experiences related to their relative’s incontinence from other aspects of caring. Rather, they recounted their experiences of their individual caring situation as a whole.

Nevertheless in Sweden, when asked direct questions a number of times about their experiences of helping their relative with incontinence care, several carers expressed that they were for the most part mainly concerned with maintaining their relative’s integrity. They were aware that it was not at all an easy situation for their relative, as prior to their illness they had not had incontinence problems so that it was a significant change for them. For these carers, they reacted by doing their best to make the most of the situation and to accept it.

Several carers who were directly involved in helping their partner with their intimate hygiene explained that they tended to ‘grit their teeth’ and simply get on with it. However, one carer found it extremely difficult and felt that it was something that she should not have to do as a partner. She found the situation deplorable.

A couple of carers who were not directly involved but nevertheless helped their relative with other caring tasks, acknowledged that should the situation arise they would have no other choice but to help their relative with their incontinence care. However, they expressed that they did not feel fully comfortable doing so.

Compared to other aspects of care, most of the carers in the Netherlands found incontinence care no problem or not really different than other types of care. It was all part of their daily tasks, and it was all heavy. They have got used to the aspects they found difficult at the beginning, such as the dirty nature, the smell and the fact that you first had to ‘cross a line’ to provide this kind of care to a partner or relative.

Several informal carers compared the changing of absorbing materials to the care of a small child. Most of them found the situation especially unpleasant for their loved one and not for themselves. Still they said that this kind of care was not pleasant and some had feelings of shame or difficulty accepting the situation in the beginning.

Informal carers said that to some extend, their relationship changed due to incontinence care, because of the intimate nature of it. Most of them said that years ago they would never have expected to be doing this type of care.

*Feelings of the cared for*

The life of people with incontinence is complicated. They are often bedbound, dependant on help from others, which may cause unpleasant feelings, sadness, crying, and restricted by social contacts avoiding them. The fact of how a person cared for perceives the situation may somehow have an impact on the carer. The cared for person’s feelings depend on whether he/she realizes his/her condition.
Incontinence is hard to accept for people being cared for who are cognitively aware of their situation but suffering from physical problems. As is the case in Italy: Some older cared for people reacted by crying and suffering from depression. Some of them were ashamed, like a 65-year old woman who has been suffering from incontinence for ten years. She is very depressed and desperate. Her daughter described her as very frail from a psychological point of view.

“A month ago we took a walk. We had to drive to another town. It should have been three quarters of an hour between the time we left and the time we arrived. She went out of the car and the seat was wet. She started crying saying: “I am always sacrificed, let's figure out if it happened to me in another place with other people ... so there definitely is some inconvenience.” (Italy)

Others react by getting angry, as they do not want to be physically touched and seen naked and fragile. In particular one out of our three male cared for persons, is very angry about his incontinence.

“He doesn’t want to be cleaned and changed, he is not helpful, he sends us away by swearing at us, which he never used to. He has become another person.” (Italy)

Also in Slovakia the situation and life of clients with incontinence may evoke awkward feelings, sadness and crying. Their perception of their condition is important for the carer. Naturally, with many people it is difficult to make a judgement – mainly if the incontinence results from cognitive impairment. They can feel various stages of anxiety, sadness, discomfort etc. The highest number of carers in Slovakia indicated that their relatives are often sad and cry. Others have named this as depression.

“You know, it makes her quite nervous. She’s always done everything herself... It is very annoying for her and she started telling me that she wanted to die, that she is fed up with it and she has strange feelings.” (Slovak Republic)

In Sweden the two cared for people with cognitive difficulties did not appear to be fully aware of their illness and their everyday needs for care and support. Nevertheless, the carers explained that their partner was often sad when they had episodes of urinary incontinence and felt ashamed. The majority of carers were fully aware that the experience of having incontinence problems was a difficult experience for their relative and they were concerned for his/her dignity and overall well-being.

In the Netherlands feelings of the cared for people differed with regards to their incontinence. Some felt ashamed and tried to hide their incontinence. One woman felt she was the only incontinent person, despite her daughter explaining she saw it every day at work as a nurse. The people who felt ashamed about their incontinence didn’t want to be assisted by anyone else other than their relative or partner. However, they also in some way accepted the fact that incontinence was a part of their life. Some carers pointed out that, looking back at their lives, their partner or relative considered the process of becoming continent as a very important step in life. It was difficult for them to give that up and become incontinent again.

Other cared-for people seemed to have no problems with their incontinence, but these were the people that were not really aware of their health status and the amount of help they needed or forgot about leaking accidents after a while.

Some informal carers explicitly mentioned that their loved one was happy to still be at home or need his or her carer around to feel safe, to feel loved or simply to talk to. Feelings of sadness or anxiety were reported but not regarding the incontinence.
3.2.5 Support in caring

The most appreciated support for carers is psychological and practical. For them not feeling left alone with the disease and the loved one’s disability is the most important aspect.

In Italy friends mainly provide emotional support to carers, asking them about the elderly person, calling them and sometimes visiting them. However they are not involved in practical terms. On the other hand the family, is involved in practical matters, even if the carer very rarely delegates the changing of pads to other family members, especially if they are male. In all 13 Italian cases, the family network offers psychological and practical support.

In Italy the most useful support is represented by the Migrant Care Worker, hired by the carers when they are employed and can’t count on other kind of family support. Some informal carers who don’t have MCW help would like to have it a few hours a day.

Experts’ advice and senior carers’ experiences are highly appreciated by some carers, in particular those preventing bedsores or skin irritations.

For one carer, who works with disabled people and cares for her father suffering from Alzheimer, her professional know-how was the greatest help in managing incontinence.

For two carers pads represent the greatest support to better manage the urinary leakages. For one main carer a “relief” carer would be useful, that is someone who could care for her incontinent mother most of the time.

“Experts’ advice was the greatest help for avoiding bedsores: they suggested a good cream. We tested it and it worked very well.” (Italy)

Several professionals can give advice and information to carers about dealing with the specifics of incontinence care. Mainly the support comes from medical and nursing staff. In a few cases (10%) a social worker, an occupational therapist or a physical therapist gives advice. A private care worker has given support in almost on third of the cases spread across the countries.

Informal support can be given on a daily or weekly basis. Any help from any source is welcome for the carer of a relative with incontinence. It will enable the carer a brief respite, have some time for himself, for handling his own problems and duties (a visit to a doctor, dealing with administrative tasks), time for hobbies. This help can be provided by family members, friends, neighbours and formal carers. The carer is mostly helped by other family members, as is the case in the Slovak Republic and taken into account if there are any relatives, or if they live close by. Carers of elderly relatives with incontinence evaluated positive advice and help, which they get or used to get from formal carers.

The advice may vary, like how to take care of a person with incontinence, practical activities, how to change incontinence products, how to wash and clean the person in bed etc. Paid care services are not very popular in Slovakia. Only one carer stated that he uses a paid carer, however, only when he is at work. Carers, who had or still receive professional help, use their knowledge and practical advice. Many of them were pleased to learn certain practical skills, which have made their work easier. They have learned how to do the washing and cleaning, and how to change incontinence products etc. Some of them have learned how to prevent bedsores.

The greatest practical help that was received by the participant carers in Sweden was home help services. In a couple of cases, home help staff came to their home several times a day (and at night in one case), which allowed the carers concerned to be able to prepare food and get themselves ready. They were then responsible for their relative’s incontinence care in between these times. In one case, a carer had help from her daughter who came home and gave her mother a short break as often as she could. However, overall the carers received relatively little physical or emotional support with regards to their caring situation in general and, more specifically, with regards to their relative’s incontinence care. The majority of carers did not directly mention that they had moral or practical support from other family members/relatives or friends. Thus, it can be argued that they were socially isolated.
In the Netherlands informal carers felt quite appreciated for the care they provided, but not always supported by family, friends and formal carers. Still, the greatest help came from relatives, in the form of emotional support and practical help and formal carers, in the form of practical help. Some (older) informal carers explicitly mentioned the joy of visiting their children and grandchildren and felt emotionally supported by those visits. Being able to do things for themselves, while someone else took care of their partner or relative, was highly appreciated by the informal carers. Stable informal support at least daily / weekly

All informal carers had eventually found the right incontinence products for their loved one but for some, it took quite a while. They would have liked some help with the search.

“My brother says: “When you need me, I don’t care if it’s in the middle of the night, when you need me I’ll get in the car.” (The Netherlands)

“Someone is allocated to you as a contact person. That really helped me a lot, she explained everything and came up with ideas.” (The Netherlands)

3.2.6 Suggestions from carers

For the interviewed carers in Italy it was very hard to reflect on, understand and then provide examples of support and aids that might improve their quality of life. They were divided into two groups: the first one gave practical suggestions, the second one psychological advice. On the one hand, some carers faced many difficulties when the elderly people were discharged from the hospital and returned home after the acute episode that caused their disability and therefore their incontinence. They experienced moments of disorientation and despair. According to them some training from experienced health-care operators to newly un-experienced carers would be useful to teach them how to change pads, prevent bedsores and to treat a disabled elderly person, at least in the first period (minimum 10 days) straight after the onset of the disease and of incontinence.

“At first we needed someone who was on our side for at least ten days, someone to tell us what we have to do, because at first I did not know what to do, and at the same time it would be useful to find the person in these offices to tell you where you can find the right services” (Italy).

Some other carers would appreciate some practical tools and aid for the older person’s hygiene, like shower chairs or raised toilets. Two carers would like a migrant care worker, however the elderly people concerned do not accept strangers. Certain interviewees suggested to try to have a positive attitude in order not be crushed by the burden of, remembering the love that links a carer to their parents and considering ageing as a normal and natural phenomenon, leading to the end of life.

Carers of relatives with incontinence in Slovakia perform hard work due to physical effort, time, spent with a loved one, psychological problems etc. Their idea of things that would make their life easier was associated with things that would make washing, cleaning and sanitation simpler. Also they suggested technical and mechanical equipment, which would reduce physical effort in care of a person with incontinence, and also make life easier for the person being cared for.

A couple of carers in Sweden experiencing significant stress in their caring situation expressed the need for regular periods of respite care to enable them to rest, recuperate and have some time for themselves: “If mum could be somewhere else for a couple of weeks, so that I could have a complete break from it.”

A carer openly expressed ambivalent feelings about the need for help and support. She was aware that she needed respite care in order to continue to manage caring for her husband. At the same time, she was plagued with guilt as she had a loving husband. However, for another carer the of moving to sheltered accommodation with her husband was important so that they could continue living together but also have access to increased help with daily care as well as the overall responsibility.
Carers in the Netherlands found it difficult to come up with suggestions that would improve their situation or would make life easier for them. Most changes related to moving. Adaptations in the house were in most cases already implemented, like a shower chair, an extra shower downstairs, clothes with Velcro tape, sleeping downstairs, a raised toilet, etc. Only two informal carers still needed adaptations in the house. When suggesting several options, the choices were diverse. Most carers were drawn to the idea of respite care.

More professional help was not really needed by most informal carers, but sharing the care with friends and family would be more helpful. Some carers reported that they were not completely satisfied with the quality of care from formal carers or nurses or the amount of support from the general practitioner. The opinions on informal carer support groups were diverse. Half of the carers would visit such an initiative, but not if it would take too much effort to find it. Another helpful option would be a consumers’ guide to select appropriate incontinence products, because formal carers could not always provide sufficient information on this topic.

The advice that carers would give to novice carers in the Netherlands was to be prepared for a heavy task and suggested to share the care with others, take some time off every now and then or at least talk about it with family and friends. They would give practical advice or just talk about more pleasant topics than their problems.

Carers made several suggestions concerning what kind of support they would like to receive from different experts and care professionals.

In all countries there was a need for accessible information dealing with types of help or support. Except for Swedish interviewees the carers would like to see adequate advice from care professionals, available consumer guides for incontinence products, more effective incontinence products, training and education in incontinence care, more carer support groups, aids and home adaptations and more sharing of care with their family.

More help with planning of future care was considered important, except for the interviewed Italian carers. In Slovakia more than half of the interviewees would like to see more money available. Respite care and more practical regular help from formal carers would make life easier for the informal carers in all the countries participating in this study.
4 DISCUSSION OF THE KEY RESULTS

What are the most important findings from the interviews? In this chapter we first present a summary of what we have found as important issues to dwell on. We compare the outcome with the result of the literature review. We end this chapter by highlighting the way we conducted the study, in other words we look into the method used with its limitations and including ethical considerations.

4.1 Summary of findings

Participation in this study

The Slovak Republic had no problems finding carers who fitted the profile and wanted to participate in the study. Sweden had difficulties with recruiting carers due to the lengthy process with securing ethical approval and the committee's requirement for formal informed consent from the cared for person as well as the family carer. The Netherlands had difficulties finding carers, so they interviewed fewer carers than expected. Italy found only female carers.

From the carers that were interviewed 81% was female. In the South of Europe (Italy) only female informal carers participated, mostly daughters (92%). In the rest of the countries there was a more equal division between children and partners. In The Netherlands the division between female and male carers was most even.

From all the carers 88% is married with the care-for person or are living together. Most carers are 65 or older (52%), except in Slovak Republic, and retired (48%). There is a significant difference in age between carers in Italy and Sweden and between Sweden and carers in the Slovak Republic.

Most of the carers have a medium-low level of education.

Reasons for taking care

There were many reasons for taking care of a partner/relative. But in all countries most carers found it natural, especially when care had become gradually more intensive over time. The most frequently mentioned reasons were: Sense of duty, love, marriage and prevention of admission to a care or residential home.

Nearly all of the carers mentioned that financial aspects weren’t a deciding factor.

Daily routine

The daily routine of carers includes multiple care activities, so the care is not only focused on incontinence. In all countries caring was time-consuming. But it was not especially the incontinence care that was time consuming, also the care for the person with cognitive impairment and/or physical impairment (cleaning, washing, feeding, etc.).

Carers reported that the incontinence care was an extra burden when the person cared for suffered from dementia, because of their behavioural problems.

Problems with incontinence (care)

Carers in all countries responded very differently to the problems associated with incontinence (care). Some carers didn’t have any problems with the incontinence (care), but on the other hand many found it hard to deal with. These problems were mostly related to having to clean and assist with incontinence very frequently or at inconvenient times of the day.

In all countries physical problems, like back pain, joint pain and tiredness, were reported by the carers. Not only the incontinence care like changing pads gave problems, but also the need for constant watchfulness was considered a major issue.

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5 A summary of the results based on the four national reports attached as appendices to this document.
Restrictions
Restrictions that were reported by the carers from all the four countries were: constant worry for the partner, feeling tied to the home, fewer social contacts, social isolation, trapped by a daily routine/schedule to change the incontinence material. In Italy carers reported that they didn’t want to invite friends over because of the bad smell.

In the Slovak Republic younger carers (daughters) felt limited in their career, because they were forced to reduce their working time.

Informal carers’ feelings in general
Carers in all countries wanted to keep their loved one/relative at home for as long as possible. Even if this meant they had to take on a lot of work and care.

The change of roles between the carer and the person cared for was mentioned in all countries by the carers. The change in character and relationship had a huge impact on the informal carers: The relationship between husband and wife had become a relationship of patient and carer or parent and child. Carers missed the love and affection they used to have together.

Informal carer’s feelings about incontinence
Informal carers in the four countries reported all sorts of feelings. If they found the care unpleasant, it was especially for their partner or parent, being independent and in need of very intimate help constantly. This was more the case for daughters and sons (in law) and less for partners.

Most carers found the incontinence care unpleasant in the beginning (‘bad smell’, ‘dirty’), but got used to it after a while.

Feelings of people being cared for
All countries reported feelings of sadness, shame, irritation, depression and humiliation for the partner/spouse. These feelings were mentioned by the people being cared for but not always necessarily relating to their incontinence.

Support
The main support to the carers in all countries comes from the family network that provides practical and psychological aids. When the family network is too weak, the carers ask for help from a formal and professional carer, for example in the Netherlands, or decide to hire a migrant care worker like in Italy. Many interviewees found experts’ advice very useful in how to better manage the caring situation and the incontinence care in particular.

Suggestions
All countries reported the following support as being particularly welcome:
- Practical help from care professionals
- Advice in coping and assistance (respite care ⁶)
- Practical advice and instruction on how to deal with incontinence products and the prevention of decubitus ulcers.

4.2 Comparison with literature
Six key issues arise from the findings as items common to all the four countries involved in this study. They also confirm the statements from the literature review.

Extra burden and time consuming
It is difficult to differentiate incontinence care from the overall care situation. We can say that incontinence represents an extra-burden always and in particular in case of very disabled and elderly

⁶ Sweden mainly reported the need for respite care and they did not request the need for practical advice and instructions
people with dementia. Even when elderly relatives don’t have cognitive problems, the carers have to frequently remind them to go to the bathroom and for this reason and for the constant need of watchfulness the incontinence management is deemed a very time-consuming and stressful activity.

Acceptance (of pain)
The carers reported they manage the leakages because the old person needs it and someone has to do it. They do not feel disgust and accept the situation but they feel sad for the health conditions of their loved one. Although the literature reported that the carers did not consider leakage handling a discreditable work.

Physical exhaustion and emotional weakness
Physical tiredness is the first and more widespread consequence of incontinence management related to back pain, tendinitis and other problems derived from the frequent physical efforts. Moreover, the carers often suffer from anxiety and emotional problems.

Social isolation
The carers are not free to go away with friends and travel because they cannot leave the relative alone. They do not invite friends at home for fear of bad smells and day by day their social bonds become weaker and they become more and more alone.

Family network
The carers receive support from other family member firstly and from other private paid services.

Need of practical support, respite moments and training
The carers suggested more practical support to be able to have a break from caring and respite moments. Moreover, they reported the need of attending training courses to learn how to manage the care of their old relatives and handling their leakages. Contrary to literature statements found, the interviewed carers reported they didn’t need a consumers’ guide, but rather somebody who can stay with the elderly people and take care of them for a few hours per week.

4.3 Method discussion

One of the main strengths of this study is the use of qualitative and quantitative data analysis. On the one hand the qualitative approach helped the interviewees to open up to the interviewers, through an empathic and confident relationship. Thanks to the semi-structured interview the carers spoke openly and told honestly about their quality of life, care situation and their emotions in the majority of the cases. On the other hand, the quantitative data allowed to describe and contextualise each situation in light of the level of disability, kind and frequency of support measured by a quantifiable method.

The qualitative research generally needs very skilled interviewers, because this kind of survey goes in depth touching very sensitive and private areas of the interviewees’ life. In particular this happens for the topic of incontinence, related to an intimate and sexual sphere of life and, as we know, considered a taboo subject. For this reason, the interviewers were selected from psychologists, sociologists and nurses experienced in qualitative research, interviewing and qualitative analysis. They managed the interview setting very well, thanks to their professional background. Moreover, in some countries, the name and contact details of a psychologist or of a counsellor was given to the participants, in case they wished to continue to discuss their situations with someone, after the interview.

Generally the carers were extremely grateful that someone listened to them and asked them about their experiences and situation. Some carers particularly stressed by the burden of care, moved and cried during the conversation and others complained about the ineffectiveness of public care services.

As for the limitations of the study, we found three kinds of problems: problems in recruiting informal carers, matters related on the very sensitive nature of the object of this research and the difficulties to achieve ethical approval.

Problems of recruiting carers
Each country found some difficulties in recruiting informal family carers of incontinent old people available to be interviewed because of social and psychological problems related to this topic. The study gives attention to family carers, but it was not simple to find people matching the selection
criteria, as incontinence is the first reason for delegating the care of the elderly person to a rest home or a private formal carer, as we know from the literature.

In the case of Italy, in particular, it was not possible to find a male the primary carer that satisfied the selection criteria within the time frame of the field study: the only man that indirectly took part in the study was the husband of a woman caring for her mother and who actively helped with intimate hygiene although he was not considered as the primary carer. This suggests that when it comes to a man giving care to an incontinent older relative the tendency, in Italy is to delegate the caring to the female members of the family or to hire a private care worker, who takes care of the most demanding tasks, including toilet assistance (9,10,11). This is one of the first tasks delegated to a private worker.

In the Netherlands many carers were ashamed to talk about this topic and some organizations did not want to bother the carers because they were overburdened.

The same problems of carers overburden posed in Sweden, where the informal carers were too busy to be able to participate in the study. In this country the process for ethical approval delayed the recruitment very much because informed consent must first be obtained from the people cared for prior to obtaining consent from their family carer.

The Slovak Republic also had many problems in recruiting people. The research team decided to look for the appropriate carers in the wider geographical area (two regions). Except for that, in the Slovak Republic one used the possibility of paying for respite services for those carers who required them in order to participate in the study. The combination of these ways helped the research team to complete the research sample.

Ethical approval was obtained by national committees according to each country’s regulations, except for the Netherlands that did not apply for ethical approval. Sweden, in particular, had many problems in achieving ethical approval due to the long process requested, that slowed down the beginning of recruitment.

The Study Consortium planned to gather 16 interviews per Country (64 in total) but, for the reasons previous explained, three countries of four gained fewer interviews than the scheduled number, caring out a total of 48 interviews.

The difficulties encountered in recruiting people available to be interviewed confirm the fact that the incontinence is still a sensitive topic not easy to talk about.

**Relationships between interviewers and interviewed people: feelings and reactions**

In all countries the interviewers were able to establish a confident relationship with the interviewed persons who talked openly and honestly about their situation in the majority of the cases. They were extremely grateful that someone listened to them and asked them about their experiences and situation. Some carers particularly stressed by the burden of care, were moved and cried during the conversation and others complained about the ineffectiveness of public care services.

An Italian interviewer reported that the interview had been an opportunity for the carers to tell of their personal difficulties. They experienced it as a way for Public Institutions to be interested in their lives and they could explain their ideas, feelings and suggestions about the care of an elderly family member.

In Sweden one carer said that doctors or nurses had never asked her, when her husband had been admitted into hospital, if she would manage to take her husband home and care for him. She explained that they had simply taken it for granted that she would care for him at home and even though a year had passed since this incident it was a significant event for her, which she recounted during her interview. As often happens during qualitative surveys, many carers cried during the interview, and explained how they must always be strong and that they never got the opportunity to express how they really felt.

The Netherlands experience is similar: the researchers reported that although some carers pointed out that the interview took some of their limited and valuable time, they took their time to answer the questions over a period of about one hour and fifteen minutes to two hours and fifteen minutes. Main reason for participating was the hope that the information from their interview would help to make a difference in improving informal carer support.
Interviewees’ behaviour towards the topic

In Italy and Sweden, the interviewed carers had no difficulties talking about “incontinence” on the side of “verbal communication”, since they considered faecal and urinary leakages natural problems related to ageing. Nevertheless, on the other side of “non-verbal” communication, the interviewer found the carers very stressed, sad and often angry. Two of the angriest interviewees answered quickly as they were irritated by questions they saw as obvious and private.

In the Netherlands, on the contrary, some interviewees found it difficult to talk about incontinence at the start of the conversation and they had some trouble using terms such as ‘faecal incontinence’, ‘diaper’ and ‘clean their relative’. The same thing happened in the Slovak Republic, where some sons who were caring for their mother were puzzled when they should talk about incontinence and they preferred non-personal expressions like “it is being prepared”, “it is being done” and so on. They also openly admitted the problems when providing incontinent care for their mothers and described it as: “you know I am a son”, “I am a man and it is different compared to daughter”.
5. CONCLUSIONS AND RECOMMENDATIONS

Although incontinence is a widespread and very common ailment among old and less old people, it is still quite an unexplored item due its sensitive nature. The findings from this study confirm that incontinence management is a burdensome and a very time-consuming activity that increases the difficulties derived from caring for an old disabled person.

In this section we would like to give some recommendations for practitioners, policy makers and researchers.

PRACTITIONERS

Hospitals and other care institutions should have to plan training courses and services to accompany the carers of old people discharged from hospital wards in order to assess the type and frequency of leakages, to help carers to manage them, to choose the right absorbent products and to avoid bedsores.

General practitioners should be more alert to the possibilities of giving advice, training and support by professional carers.

It is crucial that professionals recognise and value family carers of older people and acknowledge their expertise. At the same time, it is important that they are able to reach out and find carers early on in their caring as many family carers are elderly themselves and have health problems.

For these carers, their responsibility is 24 hours a day 7 days a week. It is important that they are given sufficient help and support so that they are able to continue caring and maintain their own health, otherwise, a crisis situation is likely. This study clearly highlights carers’ overall situation. Therefore, professionals’ understanding of carers’ situation should be given more attention in education and training programmes.

POLICY MAKERS

Policymakers should be more aware of the possibilities to relieve the burden of so many carers of patients dealing with an illness in combination with incontinence. They should look into more solutions on regional and local levels for respite for the informal carers as well as other support systems for the family networks.

More awareness of the growing problem of incontinence should be tackled, and guidelines for distribution of adequate information of services and good examples of incontinence care.

In some countries national, regional and local health systems should be enhanced to provide a better quality of absorbent products at lower prices.

European guidelines concerning incontinence care should be drafted.

Education packages should be available for patients and carers regarding incontinence care and also for health and social care professionals who come into contact with patients with incontinence problems and their family carers.

There is an urgent need for a comprehensive person-centred needs assessment for carers including entitlement to a package of care that includes the practical and emotional aspects of caring for a relative with incontinence.
At the level of national EU member states there should be measures regarding quality incontinence products at an affordable price to the (health) care provider.

RESEARCHERS

In the light of the study results, it would be useful to deepen some aspects of the incontinence care in relation with an illness such as dementia.

There should be research-action projects that schedule the application of a protection plan for incontinent elderly people after their discharge from hospital, a system of monitoring of how to improve (or not) the quality of life of elderly people supported by this service and finally a system of assessment of the outcomes.

Not only health care improvements in the field of incontinence care, but also welfare aspects in the support systems available should be more subject to research. More studies should look into factors that could alleviate carers in their daily tasks: new possibilities for reducing the psychological and physical burden. In other words, studies exploring appropriate health promoting and health maintenance intervention studies for family carers are needed.
REFERENCES


7. Cheater FM. (2008). Caregivers living with stroke survivors who were incontinent had minimal social interaction and felt socially isolated. Evid Based Nurs, 11(2):64.


**ANNEX 1 LIST OF PARTICIPANTS**

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ANNEXES 2-5 National reports

ANNEX 2 National Report from Sweden

Introduction

Globally the numbers of older people within the general population are increasing. In Sweden in 2009 17% of the population (roughly 1.6 million people) were over the age of 65. This figure is likely to increase due to increased life expectancy and the high birth rates during the 1930s and 1940s. Whilst the majority of older people are relatively healthy and remain living in their own homes up until an advanced age, there are nevertheless a range of health problems that are increasingly common in conjunction with advanced age. For example, two thirds of all those people diagnosed with cancer are over the age of 65, which together with heart and circulatory illnesses constitute the most common causes of disability (National Board of Health and Welfare Sweden, 2009). This is also reflected amongst those older people living in nursing homes, where residents require regular help and care with regards to personal activities of daily living. Many older people wish to remain living at home for as long as possible. However, with the reduction in the number of nursing home beds and efficiency drives within health care in more recent years this has led to more seriously ill older people being discharged home from hospital despite the fact that many are in need of continued nursing care and rehabilitation. Thus, it is frequently family members that bear the brunt of their elder relatives' care and support (NBHWS, 2009).

Urinary incontinence (UI) is also a problem, which has a higher incidence with advanced age (Aggazzotti et al. 2000, Andersson et al. 2004, Stenzelius et al. 2004). At the age of 50 approximately 12% of the population in Sweden report having UI (SBU, 2000) and this figure rises to 31-42% amongst people over the age of 75 years of age (Stoddart et al. 2001, Stenzelius et al. 2004). Common causes of UI include the following: age, gender, hereditary factors, overweight, vaginal deliveries, neurological illnesses, chronic illness and prescribed medications. As well, reduced mobility and the increased time taken to get to the toilet in time is also an important contributory factor of UI. In other words there are many risk factors that are related to old age (SBU, 2000). This also concerns the prevalence of faecal incontinence where 16.9% of older people over the age of 75 report this problem which in turn is associated with other co-existing illness and vulnerability (Stenzelius et al. 2004). For many people both urinary and faecal incontinence are a taboo laden subject, which gives rise to feelings of shame and guilt as a result of a lack of control. As a result, for many people it is a problem that is difficult to talk about and to seek help for ((Andersson et al. 2004, Stenzelius et al. 2006, Stenzelius et al. 2007 and Andersson et al. 2008). Many of these emotions are also described by carers who describe a constant fear for leakages or accidents in communal settings, social isolation, a changed role as a carer with reduced intimacy and sleep problems amongst others (Cassells & Watt 2003).

1. Informal carers and cared-for people

1.1 Recruitment

In Sweden, the informal carers were recruited via the urological department or with help from two nurses working within home nursing care in the same municipality. The geriatric clinic and the carer centre in the municipality were also contacted regarding the study. However, despite this variety of contacts it proved difficult to recruit carers to the study. A critical factor was lack of time on the part of the carers and many whom were contacted felt overburdened with their situation to manage to participate in the study.

1.2 Characteristics

The majority of participants were female carers (ten women and one man). All except one were spouses/partner who lived together in an apartment or house. None of them had children who lived together with them in their home. A daughter who was interviewed lived in the same rented apartment block as her mother but she had her own apartment. Four of the cared for persons had daily help from home care services in the municipality (ranging from two to six times a day) whilst only one had occasional help with cleaning and shopping. Three of the people cared for attended a day centre at least once a week.
2. The care situation

2.1 Main medical reason for care

All of the participants started caring for their respective spouses/partner/mother due to the onset of chronic illness/es. Namely stroke, heart disease, neurological illness, various urologic cancers, depression, gradually increasing health problems and dementia*.

2.2 Duration of care / Modality of starting care giving

For several carers, as the onset of their relatives’ illness was insidious, it was difficult for them to specify the exact year when they began helping to care for their relative. For the majority of carers, the process was a gradual one and ranged between approximately two to thirteen years. Even for the stroke carers, the onset of caring tended to be gradual as their relative also had other co-existing chronic illnesses, such as prostate cancer. For the majority of cared for persons, incontinence problems began approximately two years ago and in one case over a longer period of six years.

2.3 Reasons for taking over care

For the majority of carers, helping to care for their relative was seen to be a natural extension of their relationship. For the spousal carers, they perceived their caring role to be a fundamental part of their marital relationship and for love

‘The problem grows little by little and I’m there all the way, so there’s no pause just because he’s poorly. I don’t care any the less because of this other than that I’m with him and I try to help him the best I can’ (2)

I’ve grown with this. I know how Åke is’ (8)

Whereas, for one carer who was a long-term partner, she primarily took on board her caring role out of a sense of duty. She explained that her partner did not have any other relative living close by to care for him. Also, she was highly dissatisfied with the lack of quality of the respite care services they received so that she felt that there was no other alternative. In the case of the daughter, she explained that she had always had a close relationship with her mother. Thus, it felt entirely natural for the daughter to help her mother so that she could stay at home as the daughter lived close by. Several carers mentioned the importance of enabling their relative to stay at home as their relative had not previously enjoyed their short-term stay at a respite care setting or rehabilitation unit.

I don’t want him to sit there with all those who are demented. Roland doesn’t even want to eat there. I said, ask the girls so that you can have your food in your room because he felt that it was unpleasant, he didn’t want to sit with those that dribble and so forth. He isn’t awkward in that way, he could certainly be somewhere else but not amongst demented’ (4)

2.4 Daily routine

All the carers found it rather difficult to distinguish their help with incontinence care from the rest of their caring tasks, rather they tended to talk about their caring situation as a whole. All of the spousal/partner carers looked after all the household chores such as food shopping, food preparation, washing the dishes and washing clothes, house cleaning and running the house.

All of the cared for persons experienced problems with leaking urine and/or urinary incontinence at least daily and/or during the night. A couple of cared for persons also sometimes experienced faecal incontinence. The majority of carers helped their relative with their personal hygiene.

Several carers encouraged their relative to do as much as possible for themselves in order to maintain their autonomy. The daughter helped her mother to wash and dry areas that she was unable to do herself, such as feet, under the armpits and her hair. However, her mother usually carried out her intimate hygiene herself as the daughter wished to maintain her mother’s dignity. Nevertheless, when her mother was ill following her stroke and also on the occasions when her mother had fallen at home, the daughter
helped her mother with her intimate hygiene. The daughter recognised that her mother will need more help in the near future, including help with her intimate hygiene,

'She’s bathed in my bath until just recently. She was very clear that I washed her everywhere but that she managed her private parts herself. It’s the last thing in some ways. I’m aware that I’ll do that if necessary, but then I’ve gone over the limit in some ways. Yes, not because I think it’s awkward but because I’m taking something away from her’ (5)

A couple of carers explained that they regularly helped with their partner’s intimate hygiene which included undressing, washing and drying the genitals and/rectum, re-dressing and applying an incontinence pad because the cared for person was unable to do so himself. Two carers whose spouse/partner had cognitive difficulties (as a result of dementia and stroke respectively) carried out frequent verbal reminders to their partner to help them to wash and dress themselves and to change and/or insert a clean incontinence pad in their knickers. In one case, the cared for person succeeded with regular reminders from the carer,

I must tell him and put out things for him sometimes. What shall I do now he says. He’s a bit confused and doesn’t exactly know what he should do but if I say to him that he should go and have a shower then he’ll do so’ (2)

However, the carer needed to sometimes check in a respectful way if her husband, for example, had actually remembered to change his pad to a night time pad.

‘For example, last evening, I said; put on your pyjamas and the little diaper, ‘Yes’ he said but I felt that he hadn’t done that so I said, ‘May I see’. So you see, he’d put on his pyjamas but not the diaper and then it doesn’t do any good’ (2)

In the other case, the cared for person was often unable to fully undress, shower and dress himself despite reminders so that the carer carried out his intimate hygiene and dressing for him,

Yes, it can be a dilemma when shall I wash him down. He does it but you know he’d only wash his wash his face otherwise (if his wife didn’t do it). Then sometimes he can’t remember which order to put on things. So I put them in order because otherwise he could easily put on my clothes as he’s so thin. So then he comes with my knickers, he just brings a pair. So I have to check’ (8)

Several of the spousal/partner carers helped their relative with changing their incontinence pad at least once during the day and a couple of times at night. All of the spousal/partner carers helped their partner with toileting and/or intimate hygiene during the night as a result of mainly urinary incontinence/leakage. This commonly involved cleaning up the area from the bed to the bathroom where their relative had leaked urine and/or helping with intimate hygiene and changing pads.

Two of the carers had home care services on a regular basis which often included home help staff getting the cared for person up out of bed in the morning and helping them with their hygiene needs and with dressing and the same routine was followed in the evening. However, the carers concerned helped their relative during the rest of the day and during the night as necessary so that on a ‘good’ day perhaps the help consisted of helping to change an incontinence pad once during the day and once at night. Whereas, for a couple of carers on a ‘busy’ day it could well involve helping with intimate hygiene two or three times during the day and at night,

‘I have to dry his backside and change his pad. He’s made clean in the morning by them (home care nursing) and in the evening. But things can happen during the day and so then I wash him down, dry him and put on a clean diaper. Things can happen at night too, so it’s round the clock’ (3)

An elder carer admitted that whilst home help staff came and helped his wife three times during the day and once during the night, he was still ‘on call’; ‘in case’ anything happened. Whilst he explained that this was not very often, he nevertheless helped his wife with going to the toilet and changing pads should the need arise when home help staff were not present at their home.
Most of the carers helped their relative with incontinence care, such as intimate hygiene and changing pads in the toilet/bathroom as opposed to the bedside. In one case, when the cared for person was very poorly the carer helped their relative with incontinence care in bed.

3. Problems

3.1 Problems encountered in incontinence care

As explained above, carers recounted their experiences regarding their caring situation as a whole rather than focusing on different specific caring tasks such as incontinence care. For example, a dementia carer explained that she found it difficult that her husband was nearly always tired and often felt the need to go and lie down during the day. She realised it was part of his illness, yet she explained that it was not an easy situation to manage.

‘He lies down most of the time and then he gets up and watches TV, we have a coffee together. Sometimes, I can hear that he’s awake at night. I tell him that it’s because he lies down so much during the day, can’t you try to stay up a bit more? But he can’t draw himself from his bed. He’s drawn to it all the time’ (2)

In order to ascertain their experiences of helping their relative with incontinence care, the interviewer often repeatedly asked follow-up questions to help the participant carer to focus more specifically on aspects relating to incontinence care. A spousal carer who gave direct ‘hands on’ help with incontinence care, (which involved cleaning up after an accident, washing and drying the affected areas, re-dressing and changing pads) did not consider it was unduly problematic. She accepted that the incontinence problems were a result of her spouse’s illness and considered that it was ‘part and parcel’ of her caring activities such that she explained that she tried to make the best of it and ‘get on with it’.

‘No, it’s nothing special with that, this is how it is now when you’re old. I’ve accepted it, it’s just the way it is’

Nevertheless, one carer found it extremely difficult to have to help her partner with his intimate hygiene following urinary leakage and/or extreme malodour. In this case, intimate hygiene also involved carefully washing and drying her partner’s foreskin as he was prone to frequent thrush infections. She found this task particularly difficult as she considered that it infringed on her role as a partner,

‘The doctor said; you should do this and this and draw back the foreskin, but ‘I can’t’ I said, ‘I refuse. I’m not doing it’ I feel… I’m not doing it, I feel he should do this himself, because it’s a bit yucky… but I know when he smells bad, so then I sit him down, he has a shower chair you know, and I say to him, sit there now and I’ll wash you down below’ (4)

As all the spousal/partner carers helped their relative at night often with toileting and intimate hygiene or due to pain, their sleep was regularly disturbed. In three cases the carers admitted to being extremely fatigued and physically exhausted which they also recognised made them emotionally fragile. They all openly wept during parts of their interview as they recounted their situation,

‘Well, what shall I do? I was up in the night as she had so much pain so I gave her a paracetamol and a bit of water. Then it was 2 in the morning and then at 3 they came (home care nursing) and by that time I hadn’t had any sleep at all but anyhow after that I went to sleep, but it’ll be all right, it must work… it must….’ (1)

All of the carers explained either directly or indirectly during their respective interviews that they needed to be ‘on hand’ should anything occur. Thus, they were constantly on guard and were vigilant of their relative’s overall health status on a daily basis. They were all primary carers so even though several had home help services, they still felt that they had the overall responsibility for their relative. In practice, this meant that they needed to be constantly alert to their relative’s needs and situation, which fluctuated from day to day,

‘You know it’s just that we can’t go a walk, well we get there but then he’s dirty (had an episode of faecal incontinence)…maybe yes maybe no… you just never know’ (8)
3.2 Impact of care on informal carer’s life

Social life

All of the carers openly recounted how their caring responsibilities for their relative had directly impacted on their social life,

“Well, I feel that I have less freedom… but I can’t really blame that on the incontinence other than that it’s his overall illness. It’s nothing to do with the weeing. It’s everything together’ (2)

Several carers openly explained that due to their relative’s illness it was often not feasible to go out socially as they had done previously. One carer admitted that their friends had diminished over the years since the onset of their partner’s illness,

“It’s like that when you can’t always be there, then your friends disappear’ (4)

The daughter explained that as her friends lived some distance away it was not feasible for her to go away for any length of time,

‘I avoid travelling, to be far away and know that Mum is lying there alone and dying, missing me when I’ve been there so long, it feels wrong. But it’s nothing negative because Mum gives me a lot too’ (5)

Another carer explained that she usually met her old classmates a couple of times a year and she had left her husband once and had her phone with her. However, she had decided that it wasn’t feasible for her to go any longer as she would be constantly worried about her husband so that she was going to stay at home,

‘They’re my old classmates, we usually meet up once or twice a year and it’s really nice. We usually have a coffee together, yes there’s about six or seven of us and now a new get-together has been agreed on. I’ve said that I’m not going as I daren’t leave Olof for so long’ (3)

She also explained how she avoided inviting friends home as their home was now adapted for her sick husband, with a bed in the living room and drawers containing incontinence aids,

‘It’s not possible to be here at home when it looks like this. It’s embarrassing you know’ (3)

All of the carers explained that they were, to all intents and purposes, largely tied to the home because they were the main carer. The majority of carers expressed that they could leave their relative for an hour or at the most two hours to do errands but they did not feel comfortable leaving their relatives for longer periods of time. One carer stated that her daughter tried to help her to have a short break and a breathing space from time to time. However, the majority of carers did not have any regular periods of respite care. An elderly carer’s wife attended a day centre once a week however he expressed that he often felt exhausted,

‘Just recently I’ve been so tired so that I haven’t even heard them when they come in, I lie down and I just wake up when they come in, because I’m so tired, I just sleep, but that doesn’t matter’ (1)

Another carer openly admitted that she would like to have a short break so that she could rest and have some time to herself.

For the majority of carers, being restricted to the home was largely a result of their relative’s illness rather than as a direct result of their relative’s incontinence problems ‘per se’. One carer explained that as a result of her husband’s stroke he needed easy access to a disabled toilet in order that he could easily sit on the toilet seat and also so that there was sufficient space for his wife to help with managing his intimate hygiene and dressing. This meant that they were unable to visit their children and grandchildren so that all family ‘get-togethers’ were held at their home as their toilet had been suitably adapted,
'If it’s one of the boy’s birthdays, we celebrate here. It’s because of the toilet, he must have the toilet. They don’t have a disabled toilet at their place, it isn’t as large and it’s difficult because then I’ve got to take diapers and stuff with me. So we’ve felt that it’s been more practical (for them to come to their home)’ (3)

Another carer explained that they sometimes visited his brother-in law, however when they did he admitted that he wondered to himself ‘how will it go today’ as he felt that it wasn’t good for him to have to change his wife’s incontinence pad.

3.3 Feelings and experiences of informal carers related to care giving in general

It was clear from interviews with several carers that they generally accepted their situation as they had a strong desire to help care for their relative so that s/he could remain at home. Overall, they expressed contentment with their caring situation. One carer explained that she gained a lot of satisfaction from her husband often thanking her for looking after him and for giving terms of endearment to her, such as stroking her face. She was aware of the fact that he did not like to bother her and tried to minimise the number of times he disturbed her at night.

‘He’s so sorry that I have such a lot of hard work with him. He says ‘If I win a million you could have it and then you could go to a warmer climate for a week’. He’s incredibly kind, so kind and thankful. Come here and let me kiss you, he says. You have it so hard but I can’t help it he says. You understand that I don’t want to send him anywhere’ (3)

However, a (dementia) carer in spite of generally accepting her situation, after careful consideration openly concluded that she could not honestly see any particularly positive aspects to their situation. She explained that she tried to be strong for the rest of the family and tried to fix everything. At the same time she expressed feeling very sad and she cried as she explained her situation,

‘It wells up inside of me as soon as…. I try to be strong for everyone. I’ve a grandchild who gets so very sad, she can’t be near him without crying. And the daughter’s also started being like this and so she just starts crying when there’s something. I must be a bit hard myself, to stand firm. I’m one of those people who’ll fix everything themselves. Stupid though sometimes’ (2)

The daughter whilst genuinely expressing her wish to continue caring for her mother, nevertheless accepted that ‘there was no way out’, that ‘this is the way it is’ and that ‘there is no turning back now’.

Two carers openly expressed their physical and emotional exhaustion from caring and admitted that they needed a break from caring in order to rest, sleep and have some time for themselves,

‘I’ve less rest now than when I worked. I’m a bit overtired, I cry so easily but that’s nothing I tell anyone about… that I’m sad’ (4)

The male carer was 78 years of age himself and despite feeling it was his duty to help care for his wife, it was clear from the interview that he was physically struggling to manage to continue caring for his wife. The female carer admitted that her partner was often un-co operative with her (as a result of his illness) and she explained that she reacted by often being angry and frustrated.

Her situation was exacerbated by the fact that she had had negative experiences of home nursing services such that she rejected their help so she now managed her partner alone. She openly stated that she had threatened to leave her husband on a couple of occasions. However, she instantly recognised that he did not have anyone else to help him and so she felt compelled to stay.

‘It’s very difficult. It’s been so hard sometimes so I’ve said; I’m leaving, I can’t manage. It wouldn’t be so dangerous if he could do something himself, but everything, absolutely everything’… (4)

In openly expressing these emotions she simultaneously expressed significant guilt and sadness and she cried during the interview,
You're only angry, he says and I reply that I'm not angry I'm just so tired... it's very hard. Today I didn't manage, I actually cried. I said that I'm going to get away from everything but then Roland hasn't got anyone at home, because neither of us have any relatives and of course no parents. So it's not possible, you can't do that' (4).

Several carers expressed that their responsibility and concern for their relative meant that they always put their partner's health first. That's to say that they denied going to the doctor themselves even if they really needed to do so,

"I should really have gone to the doctor's but I haven't done so yet. I've put it off, I think that it's not as important as Lars-Erik's ailments" (6).

3.4 Impact, feelings and experiences of informal carers related to incontinence

As outlined above, carers were really unable to dissect their specific experiences related to their relative's incontinence from other aspects of caring. Rather, they recounted their experiences of their individual caring situation as a whole.

Nevertheless, when asked direct questions a number of times about their experiences of helping their relative with incontinence care, several carers expressed that they were for the most part mainly concerned with maintaining their relative's dignity. They were aware that it was not at all an easy situation for their relative as prior to their illness they had not had incontinence problems so that it was a significant change for them. For these carers, they reacted by doing their best to make the most of the situation and to accept it.

"But you get used to it. 'You can do it' someone said to me, but the things you have to do you manage. But not everything!' (4)

'You shouldn't think that I suffer, yes, it's true that there's more pleasant things to do' (3)

'I don't feel that it's yucky and that if you think that I've worked with children so I don't think you think that then. No, I don't think that with my husband' (8).

Several carers who were directly involved in helping their partner with their intimate hygiene explained that they tended to 'grit their teeth' and simply get on with it.

'It's all right, it must be (1)

'It's just to swallow and do what you have to do' (2)

'I've just accepted it, that just the way it is' (3)

However, one carer found it extremely difficult and felt that it was something that she should not have to do as a partner. She found the situation deplorable,

'He says; 'I'm wet', it's gone through, I can't help it', he becomes a bit sad. 'We'd better take care of the shit, I say, because by that time I'm in that mood. I shouldn't say anything but I feel that I've only just changed' (4)

A couple of carers who were not directly involved but nevertheless helped their relative with other caring tasks, acknowledged that should the situation arise they would have no other choice but to help their relative with their incontinence care. However, they expressed that they did not feel fully comfortable doing so.

'I'm aware that I'll do that if there's more to do. I must do that, but then I've crossed over that last boundary in some way' (5)

3.5 Impact, feelings and experiences of cared-for people related to incontinence
The two cared for persons with cognitive difficulties did not appear to be fully aware of their illness and their everyday needs for care and support. Nevertheless, the carers explained that their partner was often sad when they had episodes of urinary incontinence and felt ashamed.

A carer explained that she felt that it was degrading for her husband to be urinary incontinent and meant that he couldn’t help it that he leaked urine. She explained that he often resigned himself to the problem saying, “It is as it”. Another carer acknowledged that her husband felt that it was difficult being urinary incontinent but that it was something he must accept at his age,

“He thinks it’s hard but as he says he must accept it and I’m old, I’ll soon be ninety years old”

(3)

One carer explained that her husband often said to her that he did not want to be a nuisance or a burden to her and he wished she did not have to help him with his incontinence care. However, at the same time he regularly expressed his gratitude to her by praising her and giving her signs of affection.

Thus, the majority of carers were fully aware that the experience of having incontinence problems was a difficult experience for their relative and they were concerned for his/her dignity and overall well-being. A carer recounted a negative episode relating to her mother’s incontinence care when she was in hospital which highlighted her awareness of and due concern for her mother’s situation,

“At the hospital they’d let her lie in bed. She hadn’t any other choice but she’d wee-d and poed (in the bed). She’d cried out for a bedpan, but according to her the staff had said, we don’t have any bedpans so do it in the bed”. She found this extremely humiliating’ (5)

4. Support and Solutions

4.1 Greatest help in incontinence care

The greatest practical help that was received by the participant carers was home help services. In a couple of cases, home help staff came to their home several times a day (and at night in one case) which allowed the carers concerned to be able to prepare food and get themselves ready. They were then responsible for their relative’s incontinence care in between these times. In one case, a carer had help from her daughter who came home and gave her mother a short break as often as she could. However, overall the carers received relatively little physical or emotional support with regards to their caring situation in general and, more specifically, with regards to their relative’s incontinence care. The majority of carers did not directly mention that they had moral or practical support from other family members/relatives or friends. Thus, it can be argued that they were socially isolated,

‘The responsibility lies with me. This has possibly irritated me sometimes. They say, you know, say if you need any help, ring if there’s something. But it’s not to actually do the things that’s difficult, rather it’s the responsibility’ (5)

4.2 Suggestion from informal carers of incontinent older people

A couple of carers experiencing significant stress in their caring situation expressed the need for regular periods of respite care to enable them to rest, recuperate and have some time for themselves.

'We go and have coffee together once a week and I try to go and be part of it’ (1)

'If I could just have a week, if I got it and knew that he liked it where he was. I think this would help me a lot… just to be’ (4)

'If there was somewhere that Mum could be for a couple of weeks, so that I could have a complete break from it’ (5)
A carer openly expressed ambivalent feelings about the need for help and support. She was aware that she needed respite care in order to continue to manage caring for her husband. At the same time, she was plagued with guilt as she had a loving husband,

‘…but you understand that if you have a husband that only says that he loves you, at night he can wake up and sing ‘You’re my entire world’. He writes small love poems and such like, I mean, shall I leave him… It’s usually 14 days both day and night. Shall I be here on my own and Lennart isn’t here?’ (8)

However, for another carer the possibility to move to sheltered accommodation with her husband was important so that they could continue living together but also have access to increased help with daily care as well as the overall responsibility,

‘It’s just this how you should organise for yourself, it can feel a bit… Yes, we’ve thought about X home, it’s there we’d like to go to. I’ve thought about it a lot of times’ (6)

5. Description of care’s profile

Table 1. Demographic details of participant family carers

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<td>Partner/wife/husband 10</td>
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<tr>
<td>Median 78 years</td>
<td>Adult child (daughter) 1</td>
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6. Description of the cared-for’s profile

Table 2. Demographic details of the cared for persons

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<tbody>
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<td>Median</td>
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7. Analysis/Summary

Participation

The major challenge for the Swedish team proved to be the lengthy process with securing formal ethical approval to carry out the study. The ethics application was duly completed and submitted, however it first underwent institutional approval at the university hospital concerned. There then followed a time delay as the team had to wait for the formal ethics committee to have their meeting and reach a decision. The team’s application was not approved outright as the committee clearly stipulated that full informed consent must be obtained from the cared for person prior to approaching the carer as it was the cared for person’s incontinence problem that was the subject for the interview. There was also some concerns expressed that dementia carers took part in the study due to the fact that persons with dementia are unable to give their informed consent. Due to the significant time delay and the short time frame of the project, the Swedish team decided not to contest the committee’s required protocol and duly approved their requirements. Formal ethical approval to carry out the study was secured on the 16th December 2010.

There were also some problems recruiting carers to the study. This was largely due to the short timeframe of the project and the Christmas holiday period so that many carers declined to take part. As well, a number of carers refused to participate as they openly expressed that they were exhausted and were unable to take on board any additional responsibilities. An observation by the interviewer is that a short recruitment time is clearly dependent on others identifying potential participants (in this case, it was health care staff), but unfortunately as is often the case if you want a thing doing well do it yourself!

The interview

The participant carers talked openly about their situation. They were extremely grateful that someone listened to them and asked them about their experiences and situation. One carer said that doctors or nurses has never asked her, when her husband had been admitted into hospital, if she could manage to take her husband home and care for him. She explained that they had simply taken it for granted that she would care for him at home and even though a year had passed since this incident it was a significant event for her, which she recounted during her interview. Many carers expressed remorse during the interview that they described their situation with their relative as being difficult. They really wanted to
continue caring but didn’t always feel up to it and it was often hard for them to express this situation in words. Several cried during the interview, and explained how they must always be strong and that they never got the opportunity to express how they really felt. In one case a social worker was called in to talk with a carer after the interview and the interviewer has had follow-up telephone calls with all the interview participants. It was evident from the interviews that the cared for persons’ incontinence problems formed a part of a larger problem and that the overall responsibility to care for their relative was the biggest perceived burden.

Reasons for caring

The main reason given for starting to care for their partner or mother was that it was seen as a natural part of their relationship. As summed up by a carer who explained that she didn’t stop caring for her husband just because he was sick. However, there was also an aversion to care services which many felt was of poor quality. Financial aspects were not a deciding factor.

Problems

The majority of carers tried to encourage their relative to change their incontinence pads and manage their intimate hygiene themselves. This was achieved via constant reminders and requests, but it also involved more ‘hands on help’ as well. Most carers felt it was troublesome to a more or lesser degree, as summed up by a carer who said, ‘It’s very hard, but it’s all right, but not everything’. Several carers meant however that they didn’t have any problems with helping their partner ‘it doesn’t bother me at all’. A significant problem experienced by the majority of carers was that they were burned out, they were tired and emotionally exhausted. In addition, several had their own physical problems such as a poor back, rheumatoid arthritis, worn out knees and hip.

Restrictions

Nearly all the participants felt tied to the home. They lived with a constant worry for their partner, which meant that they only went out and did essential errands. The majority had given up meeting friends and acquaintances. A carer described the difficulties when she herself had to go to the doctor’s. The travelling time to and from the hospital, the waiting time at the hospital and the doctor’s visit itself was a big worry for her. She felt obliged to pay for an expensive taxi ride so that she could as she expressed it ‘buy herself more time’.

Informal carers’ overall feelings

All participants explained that they wanted to take care of their loved ones for as long as they could possibly do so. Several had direct negative experiences of institutional respite care services where their relative had been for a short stay. There was a sense of deep sorrow in their stories, as they had had to adapt their entire lives in so many different ways around their relatives’ illness. They had taken on board the practical tasks of their relative’s daily needs, household chores, managed the economy, contacts with health care, and most difficult of all, they had had the sole responsibility for judging their relative’s overall condition. As a carer openly questioned, ‘How do I know when he needs to go into hospital?’ Incontinence problems formed a part of their overall caring situation and it was their overall situation, which encompassed feelings of fatigue and isolation. At the same time, it is important to highlight that many of the participants expressed a sense of satisfaction in being able to keep their loved ones at home as long as they possibly could do so.

Informal carer’s feelings about Incontinence

The carers described incontinence as a part of their entire caring experience and it was all the combined tasks together or their overall situation that was onerous. They found it difficult to describe incontinence problems on their own. The carers considered that their relatives’ incontinence problems had not affected their relationship. A carer explained that they now showed each other affection with a kiss or stroke on the cheek but she said that it would certainly have affected their sexual relationship if they had been younger. Their strategy was to view the intimate hygiene as just something, ‘to get on with’. However, several explained that there was a limit to what they wanted to do concerning intimate hygiene (such as cleaning behind the foreskin) and one of them described episodes of faecal incontinence as being ‘yucky’.
Feelings of the cared-for persons about Incontinence

They were all unanimous in their views that their partner suffered because of urinary incontinence and they felt sorry for their relative. A carer stated, ‘he didn’t think that life was going to be like this’, whereas another carer described it as humiliating for her husband. A carer who looked after her mother described how her mother was forced to wee in her pad and knickers whilst she had been in hospital and that her mother had found it extremely degrading to be forced to lie in her own urine. Her mother was now very careful to ensure that she looked after her own intimate hygiene for as long as possible which was a way for her to maintain her personal dignity for as long as possible.

Most important help identified

The most important help identified by several carers was if they could sometimes have a complete break for a week. If their relative could be at a home that they liked for a short period of time and where the staff took over the responsibility. As a carer stated, ‘To just be allowed to be’. They all explained that it would be so much easy to continue caring if they could have a break from time to time.

8. Conclusions

The qualitative interviews that were carried out in Sweden mainly involved a group of carers who were looking after their elderly spouse/partner who was seriously ill with advanced chronic illness and required significant help at home. This is likely due to the fact that the majority of participants were recruited via the regional hospital and as such they represented a group of carers with significant caring responsibilities. At least two carers described their situation as being overwhelming and the interviewer (GA), a skilled specialist nurse deemed them to be close to a crisis situation and referred them for appropriate further help and support. It is clear that despite national initiatives in the area of family care over the last ten years approximately, the latest being a change in the Social Services Act, there remains serious challenges with reaching out to carers of older people in order to be able to provide support to them earlier in their caring trajectory. The Swedish team acknowledge that this small-scale qualitative study points to the need for awareness training and education of health care staff working at the hospital and in primary care settings regarding the situation of family carers of older people with advanced chronic illnesses and ways of working with carers, together with up to date knowledge about the range of family care support services available. With regards to the study’s focus upon incontinence care, the Swedish study reveals that from the carers’ perspective incontinence problems and daily incontinence care of their relative must be seen as forming part of their overall caring situation. Similarly to the earlier findings of Hanson et al (2008) it is the opportunity provided to talk openly with someone skilled and understanding about their situation that they find most valuable (in this case, in the form of a qualitative interview), together with the opportunity to have respite care that is deemed by them to be of good quality and accepted by their relative.
9. Literature


ANNEX 3 National Report from Italy

Introduction

The incontinence is defined as an involuntary loss of urine or faeces. The urinary incontinence is very widespread among the world population as well as Italian one but in particular it affects the female gender where it is present twice as much as male one. The 8.7% of the total Italian population suffers from incontinence problems, about 5 millions of persons (AA.VV. 2006).

For women as well as for men the incontinence grows with ageing and it affects the quality of life of patients and of their carers because the management of an incontinent person is very time-consuming and stressful. (Versteeg M, Mak S., 2010).

Although the problem is so common, it is a taboo subject yet. As it concerns the intimacy sphere, people avoid speaking of it and are ashamed to let others know of their incontinence problems. Nevertheless, speak about leakages is the first step to fight and defeat them using the right therapy and absorbent products.

1. Informal carers and cared-for people

1.1 Recruitment

In Italy, the informal carers were recruited via hospital wards (3), snowballing (4), health or social care professionals (1) and using a list of people interviewed during previous studies who were matching the selection criteria (5). A Gp, the municipality home services and an association of incontinent persons were also asked to find some male carers matching the selection criteria without success, since in Italy it is very likely for men with a family member needing a frequent big support with intimate hygiene to delegate these tasks to other female family members (sisters, wives, mothers), or to hire a migrant care worker who carries out such tasks. This is a typical strategy adopted in Italy.

1.2 Characteristics

One recruited carer is a wife and the other ones are female daughters caring either for their mothers (10) or for their fathers (2).

The carers and cared for people are mainly aged respectively 57 (range 46-74) and 83.7 years (range 72-94).

All carers are married or in couple, except for one who is widow.

Three carers have a primary education, four a lower secondary education, one a vocational education and the remaining ones a secondary (3) or a university (2) degree.

Five carers are employed, 3 retired and the remaining ones either retired or unemployed.

Nine carers out of thirteen lived with the old dependent person.

Two carers were helped by an Italian care assistant a few hours a week and four by a migrant care worker (MCW) living with the cared for one. Three carers were daily supported by the informal network caring for the older person’s intimate hygiene, and another one less frequently.

Eight carers consider their relative’s memory/cognitive problems ‘severe’ (that is requiring complete care), for two of them such problems are at a ‘low’ level (that is requiring only partial care) and in only 3 cases there are no memory/cognitive problems.
The Italian sample of older persons show high levels of impairment in performing the ADLs assessed by the Barthel index (mean 31, range 0-85), either due to cognitive or to physical problems.

2. The care situation

2.1 Main medical reason for care

Seven cared-for people were cognitively impaired due to dementia. There are two cases of stroke, one of T.I.A., one of hearth failure and two of gradually increasing care need, due to multiple reasons (Tab. 1). As a consequence of the abovementioned diseases, all of them are unable to perform most ADL.

<table>
<thead>
<tr>
<th>Main reason for care</th>
<th>Interview code</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stroke</td>
<td>IT-1, IT-4</td>
<td>2</td>
</tr>
<tr>
<td>Fractured neck or spine</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dementia</td>
<td>IT-3, IT-7, IT-8, IT-9, IT-10, IT-11</td>
<td>7</td>
</tr>
<tr>
<td>Rheumatic Arthritis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>T.I.A. (transient ischemic attack)</td>
<td>IT-5</td>
<td>1</td>
</tr>
<tr>
<td>Gradually more problems</td>
<td>IT-6, IT-12</td>
<td>2</td>
</tr>
<tr>
<td>Heart failure</td>
<td>IT-13</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>13</td>
</tr>
</tbody>
</table>

2.2 Duration of care / Modality of starting care giving

More than half of the interviewed people (7 cases) started caring 3 to 10 years ago often due to a cognitive impairment of the older one (Tab. 2), and six persons started less than 3 years ago, out of which two very recently, a few months before the interview.

"Caring started three years ago, in December 2007, as the stroke affected him. He felt bad, dragging his leg. Then he went to the hospital and through the entire hospital care-path spending 3 months at the Villa Adria rehabilitation centre…“ (IT-4).

<table>
<thead>
<tr>
<th>Duration of Care</th>
<th>Interview code</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recent</td>
<td>IT-5, IT-13</td>
<td>2</td>
</tr>
<tr>
<td>Not recent</td>
<td>IT-1, IT-4, IT-8, IT-11</td>
<td>4</td>
</tr>
<tr>
<td>Long lasting</td>
<td>IT-2, IT-3, IT-6, IT-7, IT-9, IT-10, IT-12</td>
<td>7</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>13</td>
</tr>
</tbody>
</table>

Most cared-for people (9) started needing care gradually, as a consequence of being affected by slowly developing cognitive symptoms (Tab. 3). The others started to need care (4) suddenly after an acute episode of stroke, T.I.A, heart attack or heart failure.
### Tab.3 Modality of starting caring

<table>
<thead>
<tr>
<th>Modality of starting caring</th>
<th>Interview code</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Suddenly</td>
<td>IT-1, IT-4, IT-5, IT-13</td>
<td>4</td>
</tr>
<tr>
<td>Gradually</td>
<td>IT-2, IT-3, IT-6, IT-7, IT-8, IT-9, IT-10, IT-11, IT-12</td>
<td>9</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>13</td>
</tr>
</tbody>
</table>

2.3 Reasons for taking over care

The carer’s reasons for caring are mostly related to the kind of impairment and to their relative's level of care need. However, other factors do affect the decision of caring for, for instance: living close to the cared for one, being or not a single child and the carer’s feelings towards the cared for person. The choice of caring for the old family member is usually due to a combination of the abovementioned factors. We found four main reasons for caring among the Italian interviewees: sense of duty, gender scheme, sense of reciprocity and love. Among all, caring seems to be more motivated by the last two reasons.

The following quotation describes the decision of a daughter and his husband to care for her mother due to the intergenerational sense of reciprocity and to their willingness to return the past received love when the cared-for one used to care for them. In addition to this difficult situation she is an only-child.

"The main reason I care for my mother is that she lives with me. I'm an only child. So let's say it is a logical consequence [...]. She was very young when my father died, I was 18, and she has always lived with me, since she was not able to stay alone. We have been always forced to hire an overnight carer. So, my husband and I decided that if she had needed more intensive care, we would have cared for her ourselves, as she did for us when she was younger. My husband did agree and here we are " (IT-2).

Several times we understood the real reasons for caring during the conversation through the carer’s non-verbal expressions. This is the case of a woman who appears very angry at life due to her husband’s bad health conditions but also to the bad relationship between the two. She cares for him with no love, for sense of duty and she talks about him as a bad, unfeeling and selfish person, even before he had a stroke, 3 years ago.

"He has always been a person like that…he needs only to eat and drink! The rest doesn’t matter, at all! He is a beast! He is very naughty…one needs to stay with a similar person (to understand what I mean)" (IT-4).

Two women decided to care for their older family member according to a gender pattern, that is when their older parent got worst they offered him to live with them (IT-5 and IT-7), whereas their brothers did not even consider such an option.

Although we cannot consider this behaviour as a general rule, in Italy daughters rather than sons do feel particularly personally responsible or committed to their parent’s care, according to a cultural belief that female family members are more skilled or inclined to provide care than male ones. (Crespo L., 2007 and ISTAT, 2008).

Other carers care for the older persons as they have a special love relationship with them, as in the case of these two daughters.

"I realize that if manage it in another way I would feel guilty for neglecting him, and I would regret. I do what I do because I want to. I do it with pleasure. Sometimes I think I'd be a little bit jealous if somebody else would provide care instead of me. Sometimes friends ask me to go out with them but I answer: 'I'm fine with my father'. I sit next to him, he tells me silly things" (IT-10).

"It's a beautiful experience: feeling that I love her so much and that she loves me so much. Most of all it belongs to the sphere of love " (IT-12).

2.4 Daily routine
The persons interviewed have been asked to explain and to exemplify their care activities around the
clock and to give concrete examples and stories referring to their daily routine with incontinence care and
other caring tasks. This approach was expected to allow the carers to ‘open up’ and feel at ease while
telling about their caring experiences for an incontinent relative, to highlight the problems they usually
experience, how they try to overcome them, and to identify what would be useful to make things easier in
their daily lives.

It was not very simple for carers, except for two of them, to distinguish incontinence care tasks from other
forms of help they provide to the loved one.

The effort required to the carer for toileting the incontinent person, depends on the type, level and
frequency of leakages. According to the sampling rules, all older people have daily incontinence
problems. In particular, all the older persons within the Italian sample are urine incontinent, and 6 out of
13 suffer from severe urinary and faecal leakages both during the day and at night (Tab. 4).

<table>
<thead>
<tr>
<th>Tab.4 Type of incontinence</th>
<th>Day &amp; Night</th>
<th>Only during Daytime</th>
</tr>
</thead>
<tbody>
<tr>
<td>Only urine</td>
<td>IT-6, IT-13</td>
<td>IT-7</td>
</tr>
<tr>
<td>Urine and faeces sometimes</td>
<td>IT-2, IT-8, IT-12</td>
<td>IT-4</td>
</tr>
<tr>
<td>Urine and faeces</td>
<td>IT-1, IT-3, IT-5, IT-9, IT-10, IT-11</td>
<td></td>
</tr>
</tbody>
</table>

The location where carers provide incontinence care and change absorbent products depends on the
older person’s level of disability (Tab.5).

<table>
<thead>
<tr>
<th>Tab. 5 Location where informal carer provides incontinence care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bed</td>
</tr>
<tr>
<td>Toilet / bathroom</td>
</tr>
</tbody>
</table>

In the majority of cases (9), if the older one is able to stand on his/her legs, the carer prefers to change
and wash him/her in the bathroom.

“We remove her protective pants (or pull-up) in the bathroom, while she stands with her hands
placed on the sink. Then she sits on the toilet for urinating or defecating, and then I wash her on
the bidet. After that I take her naked to the room and let her wear another protective pant (or pull-
up), while she stands with her hands placed on my shoulders” (IT-2).

On the contrary, when the elder one is unable either to stand or to stay in balance, the main carer usually
changes the incontinence products while the old person is lying on the bed (3 cases). A couple of
spouses describe in detail the practise how they together change the woman’s mother:

“We place the underpad under her (for protecting the bed). He (the carer’s husband) washes the
front part of her body, then we let her turn on her hip, and he washes her back (or her buttocks).
We keep the basin near us and we use the cotton for cleaning her, since it can be thrown away.
Then we let her turn on the other hip and we wash her vulva (or intimate parts). We spread the
various oils and creams. Then we change the brief/pad. Then we turn her supine. Sometimes
we need to turn her on her left and on her right again for fixing her vest, which went up (during
these operations), and it’s necessary to change it, if it is sweaty. We usually change the
underpaid once a day (not more often), as if we change her more frequently, urine would leak
(out of the pad)” (IT-1).

Generally, besides incontinence care, the majority of carers help their relative by feeding,
dressing/undressing, going to bed, keeping company and psychologically supporting their relatives.
Moreover they deal also with the bureaucratic aspects for obtaining the free-of charge supply of pads and
State Care Allowance. They also manage the practical aspects of care and take care of the housework.
The interviewees’ stories showed that when the older person suffers from cardiovascular diseases, as stroke (IT-4 and IT-5), T.I.A. (IT-1) and heart failure (IT-13), the main carer’s tasks concern to take the cared for one to the frequent medical specialist examinations and to day-hospitals, to look after the daily drugs assumption and to check the level of INR (International Normalised Ratio) by means of specific machines or home blood tests.

On the other side, when the older person suffers from cognitive impairment, the need of a constant supervision is an additional burden to the carers.

As soon as they wake up the first morning thought of main carers of incontinent older people, besides managing the daily drugs, is to change the pads and to clean them, not only to prevent the older people from getting wet and to wet their dresses, but also to avoid skin irritations and bedsores.

In the second half of the morning, the carers who do not work carry out household tasks. Whereas the carer has a paid work, the old person stays with another family member (IT-1, IT-5) or with a Migrant Care Worker (IT-3, IT-10). In one case, the old woman can stay alone some hours (IT-6).

“Firstly we gave her the medicines, than we change her and lastly she has breakfast” (IT-1).

Many main carers told they tend to delay as much as possible the moment to go to sleep in order to change the absorbing product as latest as possible, to keep the cared for persons as dry as possible overnight, until the next change of pads, on the following morning.

For some carers, when the cared for person health conditions were very bad, every moment of the day is marked by the change of the pads, which might occur from 5 to 7 times a day, and each activity is carried out or postponed according to the cared for person's needs.

“We use to change her at about 11-11:30 p.m, to make her stay drier overnight. In total, we change her 5 times in case she does not defecate, otherwise 6, sometimes 7 times a day” (IT-1).

If the older person attends a Day Care Centre, the main carer can enjoy some hours of relief.

“In the morning she wakes up and needs to be cleaned and washed, until mid-day. She attends the Alzheimer's day care centre until 3.00 p.m., then in the afternoon she is with me, if the weather allows it, we go out, she does not walk much, anyway we sit on the bench” (IT-2).

Four (IT-3, IT-9, IT-10, IT-13) carers out of thirteen, hired a Migrant Care Worker (MCW) as they are working carers, and having a MCW constantly looking after their loved one is a strategy to combine care and work, particularly in Italy. Three MCW live with the older person. Other two carers (IT-2, IT-7) have the occasional support of an Italian private care worker, only for few hours a week, who helps them lifting and moving the care for one and supervising them.

Relieved from the most heavy physical duties such as the cared for one’s hygiene, nutrition and transports, carers can enjoy some time keeping company, psychologically and emotionally supporting the older one and “managing” the care schedule, i.e. organising tasks related to medical examinations and administrative matters to obtain different forms of support. However, when the MCW is away, generally three days a week, the main carers spend their time with their loved ones carrying out almost all caring duties, including personal hygiene.

During the other days, the daughters visit their older parents and, if necessary, collaborate with the MCW. Often the main carer and the MCW help each other and share the caring tasks, for example in changing pads.

“I visit my father every day, but there is always a private carer with him. I spend all my Sundays with him and two afternoons per week when the private carer takes her leave. However, when I go to visit him I perform all caring tasks that are necessary” (IT-10).

If the older people are shy and it is difficult for them to accept their incontinence, carers try to encourage them in preserving their capacities and self-esteem. So they observe and monitor their older family
members, helping them if they need. However carers usually tend to encourage the disable ones to carry out their own hygiene activities independently, as far as it is possible according to their residual abilities.

“I make her wash her face, I still pretend her to care alone after herself so far as it is possible, and I try to maintain her autonomy. Although it would be easier if it were I to wash her: a 5 minutes shower and it would be over. In the morning I made her wash, while I’m there, then depending on how she feels to urinate, I made her wash and get change” (IT-7).

One carer reported she doesn’t want her cared for husband to use pads, fearing he looses his residual capacities. She prefers changing his clothes and washing him up two or three times a day to encourage him to maintain continence as far as it is possible. He only wears pads when they go out for medical examinations (IT-4).

3. Problems

3.1 Problems encountered in incontinence care

We found three kinds of problem related to incontinence care: physical, practical and depending on the old person behaviours.

**Physical problems.** Back pain, tendinitis and tiredness are very common within the interviewed sample: they are the first consequences of the carers' physical efforts to move disabled old people. For this reason, two female carers need often their husband's help to move the older relative.

“I myself had urinary leakages, occasionally, due to a strong physical effort in moving my mother” (IT-3).

Emotional ones often accompany physical problems: back pains occur together with a state of anxiety and widespread tension and strain.

“Here little by little we are all suffering from back pains as we do a lot of physical efforts. Moreover I’m highly strung” (IT-8).

**Practical problems.** Among the practical problems in managing incontinence, the interviewees reported the urine or faeces bad smell, the low quality of some incontinence products and their cost. On another side, if the carers are not disgusted by the smell, they regret if the cared for ones are ashamed of their own leakages.

“The smell is the most ordinary and banal aspect of the unpleasant task one is carrying out... however it bothers you” (IT-2).

For one interviewee it is difficult to make the bidet to her mother, who is not able to stand on her knees anymore. She prefers to accompany her all the times to the bathroom to prevent her from smelling and feeling uncomfortable.

“Is it possible that **someone to invent something much higher**? Something easy would do, just a higher bidet otherwise she cannot get up... that's why I go with her” (IT-12).

Many carers reported they did not use the right or most appropriate incontinence products when the incontinence problems started, particularly due to their lack of knowledge and experience.

Some of them did spend time and efforts searching for the absorbent product that best suited their relative's needs: hypo allergic products in case of patients with sensitive skin, or absorbing pant (pull ups), which seemed to be preferred by older people with some partially remaining cognitive abilities.

The Italian Health System supplies free-of-charge pads to older people who are recognized incontinent by a special medical commission. This free-of-charge distribution consists in 90 pads and 30 draw-sheets
Some carers told that the supplied quantity of absorbent products by the Italian Health System was not sufficient, so they needed to buy additional ones. Others, whose relatives have a particularly sensitive and irritable skin, complained that the supplied pads caused allergic reactions, so they were forced to buy hypo allergenic ones.

In these cases, carers had to bear additional costs to purchase more pads, in order to change the older person more frequently, or pads of higher quality, to avoid undesirable skin irritations. They alternated the pads provided by Local Health Authority with those of higher quality and more expensive (EUR 28-30 per box), to minimise the risk of skin irritations. This procedure has in some cases led to economic difficulties. The carer of an old woman suffering from severe urinary incontinence who was not entitled to receive the free-of-charge supply of pads from the Local Health Service, complained about a considerable economic damage, for buying the pads.

For one female main carer it was particularly hard to acquire the required skills to appropriately manage her mother's incontinence, which she did use to have when the leakages started. She complained of not being trained as no one told her how to solve some practical problems, and this increased her initial disorientation and frustration, in managing her mother incontinence, making her particularly anxious and tired. She reported there are some very banal but untold tricks, which are very helpful in case of incontinence. Unfortunately nobody teaches them: one learns by doing. For example to put a rectangular pad with a cut in its middle, into the diaper for increasing the absorbing power overnight and avoiding urine to leak out from the sides. Another trick is to turn the top edge of the diaper inside, towards the belly for avoiding leakages.

“Caring for an incontinent person is an important skill which, unfortunately, no one teaches you […] : how to cut the bottom absorbent pad that you put double or to fold the edges from the inside, otherwise the urine escapes. I mean there are such trivial things, which were not told, and I'm upset with the health operator. I mean: 'why no one is explaining to you?' […] One learns only with experience. However in the meanwhile months and years go by, as one does not understand it. For example, when at night a single pad with tears is not enough, you have to put a rectangle inside […] if you do not cut the rectangle, the pee goes out from the sides so even from the big one. That is the big pad cannot absorb it. Instead, if there is a hole … it is a physical matter as it is not that every day one is thinking about the question of how the natural flow works, do you understand? The cut must be made so that the urine goes out only from that hole and not from the sides, and then it fills up the below one. Another important thing is that the absorbent on the top edge, which is on the waist, reaches only a certain point then the other part is free. If it is left smooth, so without folding it from the inside, the pee comes out and it wets the vest as well; whereas if it is folded from the inside, it does not” (IT-2).

Problems with old people’s behaviour. Six carers experienced most problems as case the older one suffered from dementia and behavioural disturbs, particularly during the onset of the disease, since their relatives did not accept using pads. At this purpose, one carer told her mother did not accept wearing pads and the carer’s effort was aimed at preventing her from tearing the pads into bits or from hiding them. When the old people start to accept incontinence, it is easier to provide care to them.

“At first it was hard because she did not want it, she used to tear it. We had to fix with tape, as it did really bother her, she felt bound. With these pants she feels a bit better. Not now, unfortunately, as she is not reacting any longer. Previously however, yes, sometimes in the morning we found it totally broken, because she did not want it” (IT-3).

“She does not say it, she remains dirty and if she succeeds in going to the bathroom she tries to manage by herself but she does a disaster” (IT-9).

Some elder ones want to go to the bathroom alone risking falling down even if the carers would rather prefer go with them. So it is hard for those last ones to be listened to and obeyed. Changing pads and cleaning the old relatives becomes more difficult in case they are not cooperative due to their disability: their bodies are heavy and hard to move.
3.2 Impact of care on informal carer’s life

The caring tasks impact on different spheres of life: family relationship and relationship with the old person, social life and financing.

Relationship with the old person. Many carers reported the actual relationship with their old parents has changed a lot, as it was turned upside down. In the past the parents used to help the main carers whereas now they are those needing care and support: for this reason daughters become mothers and mothers become daughters. Such a role change causes sufferings and embarrassment to carers.

“The relationship with my mother is turned up-down: she has turned into the daughter now! She loves me, if I ask her if I am fat (the interviewee is very fat), she answers: “No, you are beautiful” (IT-9).

Family relationships. Some carers’ family relationships were strengthened by caring. The interviews show a difference between carer’s daughters and sons as the first ones are involved in managing the incontinence, the second are not.

One of the female carers received a lot of collaboration from her daughter and three of them from their husbands in different measures, two of them are involved only in moving their mother-in-law from the bed to the chair, but not in changing her pads due to shame and embarrassment. With the exception of a main carer’s husband, who diligently cares for his mother-in-law, there are generally several gender inequalities in caring for incontinent old people.

If the old person lives together with the main female carer and her family, on one hand the male grandchildren are emotionally involved with the older one and become a sort of mediators in the conflicts between mother and daughter. On the other hand, they are not involved in personal care and toileting.

The main carer has to deal with family relationships and to mediate in the relationships between her parents, upset by the disease. As often happens within families, the under mentioned middle-aged woman struggles to find a new balance turning herself into balance point of the extended family: this changes her relationship to her mother (affected by Alzheimer), her father and sister, but it mostly changes the relationships among all family members.

“And even the relationship with my father has become a little harder, maybe because each of us sees the disease in a certain way or we accept it in a different way. Dad still does not accept my mother’s disease so he insists that she will get better. But unfortunately she is not improving and he does not accept it. We tell him: “You must accept it, you must accept the Migrant Care Worker and mom’s condition...”. Even though it hurts me as well, as I have not completely accepted it... Sometimes I think we could have done more (crying). For everyone the relationship has certainly changed” (IT-3).

Even if carers’ families feel more united in the common effort of caring for the loved one, in the majority of cases the presence of a disabled older person, the tiredness and the lack of leisure, create tension and nervousness often degenerating into an argument. In addition to this, some female carers are also mothers, who reported to neglect their own children due to their involvement in caring for their parents.

“Sometimes we explode after having spend the entire Sunday closed here alone with her constantly screaming” (IT-9).

Social life. Caring has changed a lot many main carers’ social life: caring is very challenging and the main problem is the lack of freedom to go out, meet friends or travel. Moreover they often have not any left physical and emotional resources neither to think to go out nor to actually do it.

“What weights on a little more is the lack of freedom. My husband used to be a corporate officer with an excellent pension, I could have led a completely different life” (IT-5).

“You have always to stay with her and my husband and my husband and I can not go out together anymore” (IT-1).
When we asked one carer about her social life, she spoke about her cared for mother’s social life, clearly showing that this carer is very focused on the loved one’s needs rather than on hers and has forgotten about herself.

Her words show that she can not have a social life that is not affected by her caring tasks: the few times she goes out her mother is with her. Always having a pad with is extremely important to her.

In the below quotation she tells about her very few opportunities to meet friends as she is very bound by her caring schedule.

“My social life has reduced, I have less friends, as they are much freer than I and I am always conditioned by the times, I no longer go on holidays. When I needed some to go out, they were all sick, mum and dad, so…” (IT-3).

On the other hand, the respondent rarely invites friends to her mother’s house fearing for the bad smells of leakages and dirt.

“I am afraid of having friends over at home, I hope the house is clean, nice. I mean I’m afraid with incontinence and I think: ‘hopefully everything will run fine’ (IT-3).

The social life of an interviewed carer has significantly reduced after retirement. Work represents indeed one of the most effective tools to fight the carers’ isolation back: it allows them to have their own space and some social life (Santini S. et al. 2010).

The above mentioned female carer adds her mother’s illness has taken away her serenity to plan trips and holidays, as she is scared her older mother gets suddenly worst.

One carer due to the care commitments, had to leave his volunteer activities. However this is not a burden to her, since she is glad to be close to her mother in this difficult time.

However, others do not perceive any difference in their social life since they care for, as, even before they started caring, they did not use to have an active social life.

Financial situation and work. Economic difficulties experienced by carers where both direct and indirect. They are direct if they are the result of incontinence, when the older person does not receive the free supply of diapers by the health service or when the pads from Health Service are of low quality or not enough in quantity terms. In these cases, they have been forced to buy additional or better ones.

“Economic hardship, as the provided pads are not enough. A pack of pads costs EUR 28-30. The anti-allergic ones are fine as she got some irritations from the other ones. The brand is (omissis) with three absorbency levels (the son in law speaking), because those with only two levels are not strong enough. With those it is fine, they do not break, they are made of a special paper material, which does not irritate the skin. We alternate them with the free-of-charge ones” (IT-1).

The economic consequence are indirect when carers neglect their jobs due to their caring commitments. For some working carers it was very difficult to reconcile work and care and experienced some financial consequences.

“I was on leaves, otherwise I miss paid working days […]. They reduced my holidays and leaves and I still cannot make it to get them back” (IT-6).

3.3 Feelings and experiences of informal carers related to care giving in general

We found negative, positive and ambivalent feelings related to caring.

Negative feelings concern sense of oppression, pain, resignation and anger. Some carers feel oppressed by their daily heavy caring task as well as by the sorrows for the old person situation.
"I am often so sorry, since my mother does not feel well in particular from the psychological point of view. It’s not nice for me and I feel a little bit sad. Moreover the situation will get worse as she gets older" (IT-6).

Many carers are anxious and concerned about the future, as this daughter:

"It's bad to think that going forward, however, it will be increasingly difficult to care for her, then our thought is: 'how will we manage when to keep on going will be harder?'. The only idea of moving her to an institution makes me feel bad." (IT-3).

Several carers get angry because of their lack of freedom and as they are not able to travel and go away, to enjoy some spare time for their own interests.

Disability is these carers’ greater problem rather than incontinence that is perceived more as a consequence. Resignation, sadness and fear of not being able to manage the older person occur as well.

"Caring is certainly very hard and difficult. One has to adapt to so many things, you have to swallow and bear a lot. However when in the future they won’t be there any more you can not blame yourself about anything, you’re in peace with yourself and you repay yourself of all previously made sacrifices" (IT-8).

Positive feelings. Many carers feel good when they spend time with their older relatives. They feel love and affection and they want to care for and it was their own choice. A daughter feels fine, as she won’t be guilty when her mother will die.

"I do what I do because I want to. I do it with pleasure." (IT-10).

"A beautiful thing, a nice experience, a warm welcome, feeling I love her a lot but also that she loves me a lot. So the experience is mostly related to the particular sphere of love." (IT-12).

Ambivalent feelings. Someone feels a mix of satisfaction and anger. In one case, a female carer is morally gratified but also nervous and exasperated by caring.

"I feel morally gratified but practically angry, since I care 24 hours a day. Let’s say that when one cares for an older person one feels angry, nervous, and tired. At the end of the day, when you’ve put her to bed, you’re happy and say: "my children are normal (are o.k.) even because she was there". So it’s also a way to thank her. Although I am angry and I get tired … I’m a human being I am not a saint." (IT-2).
3.4 Impact, feelings and experiences of informal carers related to incontinence

**Feelings and experiences related to incontinence.** It was not easy for the interviewed people to specifically reflect on their personal feelings related in particular to incontinence, which is perceived as part of the complex situation linked to disability.

There are various stages of the main carer’s acceptance path of an illness affecting both the **sensory experiences**, such as tolerating the new bad smells, as well as the **emotional experiences**, such as the displeasure of seeing their loved one is not self-sufficient any more.

The onset of the disease, in particular, is also the most difficult moment for the carer, who must work out what is happening, accept the cared for one’s new condition and organise the daily life differently from what previously used to be.

“It depends on the phases of the period in which it happens: at first there is a clear rejection of everything as it smells badly, you are sorry as she is your mother who is ashamed and who therefore does not let other people care for her. Then, after 5 years, it becomes something natural as it is now for me.” (IT-2).

Some skilled carers manage the incontinence as well as any other tasks related to disability. They are aware that someone must do it and they are the only ones able to do it.

“I don’t see a great difference between incontinence care and other tasks, I have to do it and it is not a problem.” (IT-1).

Others however perceive incontinence as the main problem of caring (IT-2, IT-5, IT-11). For the following carer the relative’s incontinence represents the most difficult aspect of caring, and a considerable psychological stress as it concerns the sphere of intimacy embarrassing both the incontinent persons as well their carers.

“The incontinence is the worst aspect of caring [...] Incontinence is something very ugly, very bad both for them and for us, because there are some intimate aspects ... now I got used to the smell... at first it was revolting, I was almost throwing out, now however the nose got used to it and I can handle it...” (IT-11).

One carer highlights the difference between a child’s prospect of life and that of an older person, as the first one represents a higher motivation for their carers:

“However practically each of us is naturally able to manage incontinence, there are no problems. A child has a prospect of improving living conditions whereas an older person of worsening ones. According to me, this is the reason for the frequent caring family member’s refusal to manage incontinence” (IT-3).

Other interviewees feel uncomfortable, especially if the older person is aware of his/her own incontinence.

“You are a little embarrassed, even for her - poor dear. When sometimes she has some clearness of mind, she says: “Look at the state I am in … and you are forced to clean me” (IT-3).

**Impact of incontinence.** The interviewed carers reported incontinence management has two types of main impacts on them: firstly on their reduced freedom, secondly on their physical fatigue.

According to most of them an incontinent person requires a lot of attention all day long. They often have to change the incontinent people’s pads, take to the bathroom and so they cannot do anything else.

Some carers are not even able to leave during the pads change time, so their entire day is affected by this inflexible part of the day.
The carer described in the following quotation needs her husband’s help to change her mother and is very affected by managing her mother’s incontinence.

“Yes incontinence affects us very much. For example, I call my husband to help me changing the pads to my mother, even if he is talking to someone else. I ask him to come home quickly” (IT-1).

Another female carer cannot go out with friends, as she has to wait till late at night to change her mother not to find her wet on the following morning.

“If I want to enjoy a dinner with my friends, I can not move as however she does not go to bed before 10,30 p.m. or 11. P.m. Moreover I cannot delegate this task (changing pads and intimate hygiene) to my husband or my son. I carry it out by myself. This has affected my social life a lot. Since I have been caring for her, I can no longer go out alone or with my husband” (IT-8).

All carers reported back pain and physical problems related to the physical efforts to change pads and moving their old relatives. Some of them suffered from torn tendons and other ones also from urinary leakage due to their relatives’ heavy body weight. The carers’ bad physical conditions depend also on their lack of rest.

“Even yesterday when I came home I was very tired, I prepared dinner, my neck ached and my eyes were closing down. However, clearly, you cannot go to bed as you have to give her dinner, her pills, then she watches television and then I have to wait to wash and change her” (IT-8).

3.5 Impact, feelings and experiences of cared-for people related to incontinence

Incontinence is hard to accept for those cared for ones cognitively aware of their situation but suffering from physical problems. Some older people react crying and behave as depressed.

Some of them are ashamed, like this 65 years old woman who has been suffering from incontinence for 10 years. She is very depressed and desperate. In another quotation her daughter describes her as very frail from a psychological point of view.

“My mother changes daily 3-4 big pads. For example a month and a half ago we took a walk in the afternoon, we had to drive to another town. It should have been three quarters of an hour between the time we left and the one we arrived: she went out of the car and the seat was wet. So, imagine the discomfort: she started crying saying: “I am always sacrificed, let’s figure out if it happened to me in another place with other people ... so there is some inconvenience!” (IT-6).

Others react with anger, as they do not want to be physically touched and seen in their nakedness and fragility. In particular one out of our three male cared for persons, is very angry at his incontinence. One man remains speechless and mortified.

“He doesn’t want to be cleaned and changed, he is not collaborative, he sends us away with bad words, which he never used to say. He has become another person” (IT-13).

4. Support and Solutions

4.1 Greatest help in incontinence care

The largest part of the sample benefits from the free-of-charge supply of pads and from the State Care allowance, a monetary contribution granted by the National Health Service to disables used often by Italian caring families to pay a Migrant Care Worker.

The sample can be divided into four groups of carers according to the kind of received support: some carers are helped only by other family members, others by a stronger family network and by some private paid support, few carers only by a MCW. Only one is supported by a public Daily Centre.
Only family support. More than half of the interviewed sample is not formally supported and relies only on other family members.

One of them is sometimes supported by her daughters but mostly by her husband, who cares for his mother-in-law alone all morning when his wife is at work, and every time she needs to change her pads or move the old mother (IT-1).

Another one is a wife caring for her husband. She is often the only carer as the person cared for won’t accept anybody else (IT-4). She is helped by her daughter and son, who keep the old relative company a few hours a week.

Three only-child daughters caring for their mothers and living with them are only morally but not practically supported by their husbands (IT-7, IT-8 and IT-12).

Migrant Care worker and Family network. Out of the sample four interviewed carers (IT-3, IT-9, IT-10 and IT-13) share the caring activities with other family members (sisters, brothers and husband) and a hired MCW. They visit the old parents daily spending time with them, changing pads and cleaning them in case of need. They are both practically and emotionally very much involved.

“We never leave her alone. Dad is with her and then there is the Migrant Care Worker all day long and overnight. I have also a sister, who collaborates as well” (IT-3).

Only Migrant Care Worker. When the carer is an employed only child, a common solution for providing care for the disabled and incontinent relative is to hire a Migrant Care Worker who lives with the elderly relative. Nevertheless, despite the MCW for one of the interviewee it is still hard to balance work and care.

“I visit my father every day, however the Migrant Care Worker is always there with him. I spend all my Sundays with him and two afternoons a week when the Migrant Care Worker is on leave. Nevertheless, whenever I visit him I do everything which needs to be done” (IT-10).

Day Centre. Another female main carer suffering from a strong back pain is helped two hours a day by a Migrant Care Worker. Generally the older cared for one attends an Alzheimer Daily Centre every morning, so that the main carer can enjoy some hours of relief.

“The Daily Centre can be helpful as during that part of the day, I don’t think about my mother” (IT-2).

The most appreciated support by carers is psychological and practical ones. To them not to feel left alone with the disease and the beloved one’s disability is the most important aspect.

Friends mainly provide emotional support to carers, asking them about the older one, calling them and sometimes visiting them. However they are not involved in practical terms.

On the other hand the family, is involved in practical matters, even if the carer very rarely delegates the change of pad to other family members, especially if they are male. In all 13 cases, the family network offers psychological and practical support.

“[…] Friends are a great moral rather than practical help: they call us, visit us, they ask us. Yes, it is worthwhile. We feel supported by our family as it is big and we are a lot” (IT-1).

“Doubtless my family. Both my husband and my son have always supported me” (IT-8).

Experts’ advice and senior carers’ experiences are highly appreciated by some carers, in particular those preventing bedsores or skin irritations.

“Experts’ advice were the greatest help to avoid her bedsores hurting her body: they suggested us a good cream. We did test it and it worked well indeed” (IT-1).
For one carer, who works with disabled people and cares for her father suffering from Alzheimer, her professional know-how was the greatest help in managing incontinence.

“Being a social health worker has made the difference, I’ve always managed by myself relying on my expertise” (IT-10).

For two carers pads represent the greatest support to better manage the urinary leakages. For one main carer a “relief” carer would be useful, that is someone who could care for her incontinent mother most of the time.

“The pad is the biggest support. That one first of all. Then of course someone who is constantly close to my mother could be useful” (IT-5).

4.2 Suggestion from informal carers of incontinent older people

For the interviewed carers it was very hard to reflect on, understand and then to provide examples of support and aids might improve their quality of life. They were divided into two groups: the first one gave practical suggestions, the second one psychological advice.

On one side, some carers faced many difficulties when the old persons were discharged from the hospital and returned home after the acute episode that caused their disability and therefore their incontinence. They experienced moments of disorientation and despair. According to them some training from experienced health-care operators to newly un-experienced carers would be useful to teach them how to change pads, prevent bedsores and to treat a disabled older one, at least in the first period (minimum 10 days) straight after the onset of the disease and of incontinence.

Some other carers would appreciate some practical tools and aid for the older person’s hygiene, as shower chairs or raised toilets. Two carers would like a migrant care worker, however the older cared for one does not accept any strangers.

On the other side, some interviewees suggested to try to have a positive attitude in order not be crushed by the care burden, remembering the love binding a carer to the own parents and considering ageing as a normal and natural phenomenon, leading to the end of life.

“To take everything with a positive attitude, to consider the good aspect which is the thrill of being with someone who is slowly going away, which is also nice because it’s considering that he has already lived his life and now there is a part of life in which you must accompany him and it is a something natural. Old age, death, once they used to be all experienced at home. At present ageing is considered as a disgrace and an disable one has to be put into a nursing home and be send away” (IT-10).

“Remember how much you did love her when she was healthy and remember that love multiplies while you are caring for her as it is such a great gift to be able to volunteer for someone you loved and who you love” (IT-12).
5. Description of carer’s profile

The following table (Tab. 6) describes and summarizes the main demographic features of the informal carers involved in the study in Italy.

Tab. 6 Description of carers

<table>
<thead>
<tr>
<th>Carer’s gender</th>
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<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>13 (100%)</td>
<td></td>
</tr>
<tr>
<td>TOTAL (=100%)</td>
<td>13</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Carer’s age</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Average age carer</td>
<td>57.0</td>
<td></td>
</tr>
<tr>
<td>&lt;=65</td>
<td>1 (8%)</td>
<td></td>
</tr>
<tr>
<td>&gt;65</td>
<td>11 (77%)</td>
<td></td>
</tr>
<tr>
<td>TOTAL (=100%)</td>
<td>11 (2 missing)</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Carer’s marital status</th>
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<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Married or living together</td>
<td>12 (92%)</td>
<td></td>
</tr>
<tr>
<td>Intimate relationship</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Single, never married</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Separated / divorced</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Widowed</td>
<td>1 (8%)</td>
<td></td>
</tr>
<tr>
<td>TOTAL (=100%)</td>
<td>13</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Carer’s level of education</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Cannot read nor write</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Less than primary school</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Primary school / similar</td>
<td>3 (23%)</td>
<td></td>
</tr>
<tr>
<td>Secondary school / middle or high school</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Lower secondary education</td>
<td>4 (31%)</td>
<td></td>
</tr>
<tr>
<td>Secondary education</td>
<td>3 (23%)</td>
<td></td>
</tr>
<tr>
<td>Vocational education</td>
<td>1 (8%)</td>
<td></td>
</tr>
<tr>
<td>University / similar</td>
<td>2 (15%)</td>
<td></td>
</tr>
<tr>
<td>TOTAL (=100%)</td>
<td>13</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Carer’s employment status</th>
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<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Employed (full time)</td>
<td>4 (31%)</td>
<td></td>
</tr>
<tr>
<td>Employed (part time)</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Self employed</td>
<td>1 (8%)</td>
<td></td>
</tr>
<tr>
<td>Housewife/househusband</td>
<td>2 (15%)</td>
<td></td>
</tr>
<tr>
<td>Retired</td>
<td>3 (23%)</td>
<td></td>
</tr>
<tr>
<td>Volunteer worker</td>
<td>1 (8%)</td>
<td></td>
</tr>
<tr>
<td>Unemployed</td>
<td>1 (8%)</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>1 (8%)</td>
<td></td>
</tr>
<tr>
<td>TOTAL (=100%)</td>
<td>13</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Relationship to person in need of care</th>
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<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Carer is husband</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Carer is wife</td>
<td>1 (8%)</td>
<td></td>
</tr>
<tr>
<td>Carer is son</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Carer is daughter</td>
<td>12 (92%)</td>
<td></td>
</tr>
<tr>
<td>Carer is daughter-in-law</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Carer is son-in-law</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>TOTAL (=100%)</td>
<td>13</td>
<td></td>
</tr>
</tbody>
</table>

6. Description of the cared-for’s profile
The following table (Tab.7) describes and summarizes the main demographic features of the cared for people involved in the study in Italy.

**Tab. 7 Description of cared for people**

<table>
<thead>
<tr>
<th>Italy</th>
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</thead>
<tbody>
<tr>
<td><strong>Cared for's gender</strong></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>3 (23%)</td>
</tr>
<tr>
<td>Female</td>
<td>10 (77%)</td>
</tr>
<tr>
<td>TOTAL (=100%)</td>
<td>13</td>
</tr>
<tr>
<td><strong>Cared for's age</strong></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>83.7</td>
</tr>
<tr>
<td>&lt;=75</td>
<td>2 (17%)</td>
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<tr>
<td>&gt;75</td>
<td>10 (83%)</td>
</tr>
<tr>
<td>TOTAL (=100%)</td>
<td>13</td>
</tr>
<tr>
<td><strong>Cared for's memory and /or cognitive problems (assessed by the carer)</strong></td>
<td></td>
</tr>
<tr>
<td>Absent</td>
<td>3 (23%)</td>
</tr>
<tr>
<td>Low</td>
<td>2 (15%)</td>
</tr>
<tr>
<td>Severe</td>
<td>8 (62%)</td>
</tr>
<tr>
<td>TOTAL (=100%)</td>
<td>13</td>
</tr>
</tbody>
</table>

7. Analysis/Summary

In this section we summarise the main findings for each research item, comparing them with the information we have from the Literature.

**Participation**

In Italy all the contacted persons showed available to be interviewed and they were relaxed and opened during the conversation. The interview had a cathartic power on the carers who felt free to cry and express their emotions. Most of them lived this experience as an acknowledgment for their daily, invisible and indoor job of care.

The researchers had two types of problems. The first one was finding informal carers who were the main carer handling problems related to incontinence, because in Italy many carers used to delegate the management of the urinary and faecal leakages to a Migrant Care Worker. We can say that the incontinence in Italy is one of the main reasons for hiring this kind of private paid care service, as well as it is the first reason leading the old people to a Rest Home in other European Countries.

The second problem was finding male carers, according to the inclusion criteria, due to cultural and economic reasons previously showed. These two issues made it difficult to achieve the goal of 16 interviews.

**Reasons to take care**

The main reasons for taking over care are love and sense of reciprocity, when a daughter wants to care for her parents as well as they did for her in the past. The interviewees talked about their relatives remembering the love bound that linked them each other, even if now they are living a new kind of relationship because of a role change. Nevertheless, some carers deal with their old relatives for sense of duty and lack of alternatives.
Daily routine

 Generally the carers do all activities their cared for need and related to the area of instrumental activities of daily living (IADL): they help the old persons feeding, dressing, cleaning, moving them from the bed to the chair and vice versa and naturally changing pads. Beyond this, the carers deal with house work, bureaucracy regarding MCW’s regulation or the achievement for the state care allowance and free of charge supply of incontinence materials. Besides, they keep company to the loved ones and provide them psychological support.

Problems

The interviewees encountered three kinds of problems: physical, practical ones and problems with old person behaviour. All the carers have back pain for moving, cleaning the old persons and changing their pads. The urine or faeces bad smell and the low quality of some incontinence products and the high cost of better pads are considered practical problems as well as the lack of support to clean the old disabled persons (shower chair, higher bidet) who are not able to stand up on their legs or are very heavy.

The old persons affected by dementia do not accept their leakages and try to tear the pads away and the carers find difficult manage this situation.

Restrictions

The main restriction, very common among the interviewees, is the lack of freedom. Most of them schedule all their daytime into changing pads and on the other needs of the loved one. Many carers are ashamed of bad odours and, if they live with the old person, they avoid inviting friends at home. This kind of situation often leads to social isolation.

The caring affects also the well-being and health conditions of the carers, who feel exhausted.

The incontinence has also a great impact on the financial situation of the Italian carers. Most of them reported they have to purchase incontinence products more expensive than those provided by the National Health System because the old person has allergic skin reactions dressing pads of bad quality.

Informal carer’s feelings in general

It was difficult for the interviewees to distinguish between feelings in general and feelings related to incontinence. We can say that a mix of anxiety, sadness and tiredness is the main feature of a carer of an incontinent old person. Summarising, we found three types of feelings: negative, positive and ambivalent feelings.

Informal carer’s feelings on incontinence

As for the carers’ feelings on incontinence, most of them find natural handle this kind of tasks. Nevertheless, some of them feel disgust for leakages in particular at the beginning of the illness. Perhaps the feelings about the incontinence go on with the acceptance and the working-out of the disease by the carers.

Feelings of cared-for people

Two kind of reactions are founded among the cared for persons without dementia: angry and sadness. Old women react with depressive behaviours, while old men react with aggressive one.

Greatest help

The carers of incontinent old people can count on the family network that often follows a female line: daughters, sisters and wives. When the family network is too much weak, the main carers decide to hire a Migrant Care Worker: this is the greatest help they received and it is a private aid paid by the family.
Many carers appreciated suggestions and advice by senior carers or experts about how changing pads and avoiding bedsores.

Friends have a marginal role: they provide only psychological support.

**Literature Review**

This paragraph brings together and compares the results of the Italian qualitative study with the outcomes from the literature (Veersteeg, 2010).

In spite of what literature review shows, about incontinence care being more burdensome and more time-consuming than other types of informal care, only three persons out of the 13 Italian interviewed main carers seem to confirm this statement. In the Italian study incontinence is related to cognitive problems (7 old persons out of 13 are demented): too many to state that the need of watchfulness and supervision of the cared for ones concerns only their toileting. Nevertheless, we can confirm that incontinence represents an extra burden when the care recipients are demented, because of their behavioural problems. We learn from the Literature that incontinence is discrediting: this aspect is not supported by the interviews. According to the interviewed main carers incontinence care is a physical effort and an unpleasant work, but it is not a discreditable work.

Caring for a family member with incontinence problems impact greatly on the carers’ daily life, in particular on their social isolation: many carers are trapped by fixed pad-change times and do not invite friends over at home fearing their place could smell badly. As we could expect, the interviews support the idea of a role change between main carer and cared for person, as in the present situation the carer carries out tasks the cared for one used to manage independently in the past. Some carers are angry but most of them are only sorry for their relatives’ conditions, even if they are very tired at the end of the day. The physical efforts are a feature of incontinence care with a great impact on the carer’s well-being and health-conditions, who often suffers from back pain and tendinitis or is exhausted.

The interviewed carers need practical support in order to enjoy some free time and respite moments. For such carers it was hard to name some helpful tools to improve their quality of life. Some of them provided practical advice and a few others psychological ones. Nobody suggested a consumer guide or attending informal carers support groups.

Moreover, as showed by the Literature Review, some carers would appreciate to be trained by some health care professionals to learn how to change pads, prevent bedsores and to treat a disabled person, at least in the first period after the onset of the disease and of incontinence.

The quality of incontinence products is very important to the interviewed people for managing the leakages as they reduce the carer’s physical help.

**8. Conclusions**

For most of the interviewees managing urinary and faecal leakages is a shock at the beginning, particularly when the cared for one suffers from dementia and does not collaborate. At a later stage carers learn about the best continence products and start to better manage the depressed or aggressive behaviour of the cared for person when changing their pads. Carers get accustomed to the bad smells, they overcome the sense of disgust and, at this point, the pad change becomes like any other care activities, even if remaining a very burdensome task. Cared for persons need constant watchfulness, and a physically demanding effort of carers who have to move them.

Incontinent care affects the informal carer’s life a lot. From a psychological point of view, carers often feel sorrow, sad or angry and are exhausted.

They social life is reduced and they are isolated because the incontinence management influences their daily schedule and they fear their houses smell badly when their friends come around.

Some carers’ financial conditions are not good due to the incontinence management. Some carers have to change the old cared-for persons very often, due to their fragile skin and allergic reactions. For this
reason such carers purchase major quantities of higher quality expensive absorbents and anallergic pads.

As for carers’ health and well-being, back pain, lack of leisure and anxiety are the direct consequences of incontinence care.

Some carers’ families are more united since the beginning of the care need, but during the interview they often revealed some tensions among family members due to the old person’s behaviour or to the main carer’s tiredness.

The family network is the most important support to Italian informal carers of incontinent older people. When such a network is too weak or absent a Migrant Care Worker is hired. Public unpaid support are not widespread among carers, even in case the old person is highly dependent: only one old woman attends a Daily Centre and only one receives the nursing home help from the Local Health System once a week.

The interviewees reported they had to learn alone how to change and care for their relatives, paying this effort in terms of anxiety and tiredness. For this reason many of them reckon it is important for novel carers not to be left alone, to have someone close, teaching them how to face the old loved one’s disease, disability and incontinence.

They also need practical advice to easy the contact to the National Health Services in order to obtain benefits, aids and tools to care for the old dependent person in a reasonable time.

9. Literature


Crespo L. (2007), Caring for parents and employment status of European mid-life women, Centro de Estudios Monetarios y Financieros (CEMFI), Spain, University of Alicante (Spain), http://www.ftp.cemfi.es/pdf/papers/pew/Laura520Crespo.pdf


Di Nicola P.(2003), Il difficile percorso delle donne tra lavoro produttivo e lavoro di cura in Oggidomani Anziani, Anno XVI n. 2


ISTAT (2008), Conciliare lavoro e Famiglia. Una sfida quotidiana, Argomenti n. 33, www.istat.it


ANNEX 4 National Report from The Netherlands

Introduction

Incontinence, involuntary loss of urine or faeces, has affected more than ¾ million people in the Netherlands. Incontinence is a major obstacle in daily functioning and still a big taboo. People find it dirty and are ashamed to talk about it (Teunissen, 2006). With patients who also have other health problems, incontinence leads to a further decline in quality of life. In addition to practical and hygienic problems, a lot of people with incontinence suffer from psychological problems (e.g. anger, guilt, frustration and shame), social problems (including insulation, less mobile, giving up work and social contacts) and physical consequences, such as incontinence lesions and urinary tract infections (Laycock & Haslam, 2004). It also appears that people who suffer from incontinence have an increased risk of an admission to a nursing home (Matsumoto et al, 2007; Nuotio et al, 2003). Incontinence is most common in the elderly. Because of the double aging in our country it is expected that the prevalence of incontinence among our older population will increase further (Huns Kaar et al, 2005).

1. Informal carers and cared-for people

1.1 Recruitment

In the Netherlands, the informal carers were recruited via organisations for different types of home care. In most cases, a manager was contacted via e-mail with all relevant information about the study, and asked to send this information forward to care professionals that have contact with incontinent people and their informal carers. Most care organisations did respond but stated they were not able to find any respondents, because the informal carers did not think the study was important enough or were ashamed to talk about this topic (even to health care providers). Some organisations did not want to bother busy, sometimes overburdened, informal carers with this question.

1.2 Characteristics

Mostly female partners (n= 4) of people with incontinence were interviewed, but also one husband, two daughters and one son. Except for the mothers and daughters, all informal carers and cared-for people lived together. All informal carers, except one, received home care. Help from family or friends were given less frequent.

Two daughters (informal carers) visited and helped their mothers several times a week, but did not take care of them every single day. Still, they were the persons that provided care most frequently for the incontinent. One other woman cared for had a suprapubic catheter. She sometimes still voided via the natural way and was at moments also incontinent for faeces. Home care nurses helped in that case and her husband (the informal carer) assisted them. This couple did not meet all the inclusion criteria, but were included because male respondents were scarce and this husband was very concerned with and stressed about the incontinence care of his wife.

2. The care situation

2.1 Main medical reason for care

All cared-for people were cognitively impaired, due to dementia, stroke or transient ischemic attacks. Some suffered from physical impairment caused by stroke, muscle disease, rheumatic arthritis or aging.

2.2 Duration of care / Modality of starting care giving

The informal carers were taking care of their partner or parent for two to nine years. Most cared-for people became incontinent between one and three years ago: Some suddenly, for example after a stroke, others gradually, for example due to rheumatic arthritis.

2.3 Reasons for taking over care
The main reason of caring for their loved one was a sense of duty because they were married or it concerned their mother, or because the cared-for people used to take care for the informal carer.

“We don’t let each other down, we promised that when we got married.” (3)

“I think he always cared for us very well, so now it’s my turn to take care of him.” (5)

Some informal carers reported a sudden change in their cared-for’s health status, which made the care necessary. They felt they had no choice. Others said the care became gradually more and it felt naturally. Additional aspects mentioned were the fact that the cared-for people preferred the care from their own partner or child and the fact that informal carers wanted to prevent the admission to a residential or nursing home.

“He’d rather sit in that chair all day long and wants me to be with him twenty-four hours a day.” (8)

“My mother always stated that she wanted to live in her own house for as long as possible.” (7)

Two informal carers cared for their loved one at home because they would rather be independent from formal health care. One informal carer found it completely natural to take care of a parent.

“It’s very natural to start taking care of your parents at a certain time, especially when they become invalid.” (6)

2.4 Daily routine

The cared-for people were all urine-incontinent. Most of them were permanently or less frequently incontinent for faeces. Two cared-for persons were almost never incontinent at daytime.

The cared-for people needed more or less assistance with toileting, changing incontinence materials (at the toilet or in bed) and cleaning the toilet, bathroom and bed.

Besides incontinence care, most informal carers also provided help with (un)dressing, helping to bed, showering and feeding. They did household tasks, administration and activities around the house, ordered incontinence products and arranged home care. Some informal carers felt they did everything and some explicitly stated they also did things their partner used to do, but was not able to do anymore.

“I can never sit down for a moment, I’m constantly busy with that man.” (1)

“My husband used to take care of the finances.” (5)

3. Problems

3.1 Problems encountered in incontinence care

The problems that informal carers had to face were, based on the information from the interviews, divided into three types of problems: related to the cared-for’s incontinence, physical problems and practical problems.

The informal carers that were facing problems related to the incontinence care told that their cared-for person was not able to use the toilet or bathroom without soiling oneself or the room.

“At a certain moment you notice that the bathroom and his clothes are not clean anymore, so you start helping him.” (4)
Several reasons were reported for the soiling. Some cared-for people couldn't reach the toilet in time, some couldn’t handle their absorbing materials and spilled when changing them, others were not aware of how to toilet properly or how to get their clothes back on afterwards.

“The biggest problem was that she forgot all of that [incontinence and wearing absorbing materials]. So she always tried to reach the toilet in time, but she was always too late.” (7)

This could lead to very unpleasant situations, with people staying in the bathroom naked or lying in a wetted bed. All these problems were caused by cognitive problems, physical problems or a frequent and strong need to void and in one case by the use of diuretics.

“She used diuretics for a while and at that time, she actually needed larger absorbing products.” (2)

Some informal carers also reported bad smells, because of faecal incontinence or because their loved one did not change the absorbing materials frequently.

“She smelled. She wore her pads and briefs way too long and said: “It’s such a waste to throw it away so soon”.” (2)

Another problem was that some cared-for people didn’t cooperate. They resisted help or advice from both informal and formal carers in various situations, incontinence-related and with other types of care.

Physical problems were not reported very frequently. One informal carer had sleeping problems because her husband visited the toilet frequently at night. Informal carers also mentioned that caring could be physically heavy, for instance when bringing their partner or relative to bed.

“I overload my back because he is very heavy.” (1)

Practical problems mostly had to do with the type, quality and delivery of incontinence products or with help from others. Some materials did not prevent leakage, torn apart easily or were not delivered on time in some cases.

“I’ve tried so many [incontinence] products. When I finally had something that worked, several months had past.” (5)

Others said that they would like to receive (more) help from family or support from formal carers. They were too tired to do everything alone or too busy to do everything they felt they should be doing.

“My head is just completely overburdened.” (8)

Some informal carers were not satisfied with the home care organisation and would like to receive more or better care. Or they would like to receive care from the same person every day.

“My mother is indicated for a twenty-four hour stay in a nursing home each week, to take some work off me. So I call the nursing home and they say: “Sir, we don’t provide that sort of care”. “(6)

Other problems outside these three categories (related to the cared-for’s incontinence, physical problems and practical problems) were that some cared-for people needed a lot of personal attention or needed constant watchfulness. One cared-for person drank less in attempt to prevent incontinence accidents at night.

“She can call any moment. She calls me, three times about the same topic, until I’ve been there to talk to her.” (2)

“As an informal carer, you’re very busy. It is difficult to take initiatives, to gather information [about incontinence products].” (6)
3.2 Impact of care on informal carer’s life

All informal carers said their social life had changed but for most of them, this was especially due to other factors than the incontinence care. For two informal carers, these changes were caused by their partners’ incontinence. One informal carer could barely leave the house because she needed to assist her husband to the toilet very often. One informal carer did not want to visit people because it was difficult for her husband to use a strange toilet. Others sometimes felt locked inside the house, but this was caused by other problems than incontinence.

“I always loved gardening but now, this is my garden [pointing at the balcony].” (1)

Informal carers did not think their cared-for relatives and partners felt locked inside, most of them felt no desire to go outside. This was also true for some of the carers.

Informal carers caring for their partner found it difficult to ask for help from their children or brothers and sisters, but did not think this resulted in a change in the relationship with their family.

“My son and daughter-in-law both have fulltime jobs. I can’t claim their Sunday afternoons and ask them to come visit us.” (4)

One informal carer worked for three days, while used to work fulltime, to take care of his mother. One carer arranged with her manager that she could take a couple of hours per week off to be able to take care of her husband. Another carer and her husband stopped doing volunteer work after 10 years.

No changes in financial situation were reported. However, some informal carers mentioned expensive aids they had bought for their partner or relative, such as special cushions to prevent bedsores. Others said that the financial administration regarding the formal care was very time consuming and almost too complicated to handle.

3.3 Feelings and experiences of informal carers related to care giving in general

The feelings informal carers had about the care in general differed from tiredness and being really emotional to feelings of anger and irritation.

“I’m really tired at the end of the day.” (5)

“I’m like a little rubber band with a weak spot, tears come over and over again nowadays.” (1)

One son caring for his mother said he had no future perspective at this moment.

Almost all partners were afraid something would happen to them, what would result in their cared-for being admitted to a residential or nursing home.

Some informal carers found it difficult to name positive aspects of caring, others really focussed on these positive aspects and were glad to help their loved one. And they were glad to have them around.

They didn’t want to complain, but wanted to approach the situation positively.

“If it helped to complain, I would complain, but it doesn’t help. So I don’t complain.” (3)

“I try to find another practical solution every time, it’s all I can do.” (8)

Informal carers reported that the change in relationship had a huge impact on them.

Partners (informal carers) felt their love relation had turned into a carer-patient relation or a parent-child relation. Most demented cared-for people did not show their love anymore or didn’t seem to bother about
their carers’ well-being and one demented person became very aggressive. However, three informal carers found a special way to still connect to their husband and wives by hugging, talking and making eye contact and two husbands still felt really proud of their beautiful wives.

“The two of us, we love each other, we take care of each other and we stick together.” (4)

Children carers said the relation with their incontinent parents had automatically changed or even had to change before they were able to provide this type of care.

“When your mother grows really old, it’s natural your relation with her changes. It’s happened gradually, I started taking care of her more and more.” (7)

Another aspect of the change in relationship was the fact that the cared-for person was always in first place. Carers who went out to do things for themselves felt guilty about that.

The change in the character also resulted in a need to keep their loved ones dignity by letting him or her do things alone as much as they could.

“I try to accept him the way he is. I observe him and when something goes wrong, I help him.” (1)

Two informal carers felt very criticized by their family, who thought that moving to a nursing home would be better for their relative. Some informal carers had a need to defend their loved one who was demented, because they sometimes said wrong or strange things because of the dementia.

No changes in the relationship with other family members were reported. However, some informal carers found it hard to talk to them about their problems. When talking about the situation, they felt unheard or too negative.

“Well, sometimes it’s emotionally heavy, when you need some support, want to talk about something and receive no answer.” (5)

“When you are together [with family] you don’t talk about how bad the situation is. I don’t like that, when you visit someone.” (8)

A few informal carers sometimes wished they could give up caring, because they felt overburdened. However, they realised that in that case, their cared-for would have to move to a residential or nursing home and all informal carers resisted this. They did not think the quality of care in nursing homes was better than the care they provided at home or had bad experiences from temporary admissions in the past. Some named conditions in which case an admission would be inevitable, like faecal incontinence or prosopagnosia (not being able to recognize people). Others stated that there were still enough reasons to keep caring: a feeling of belonging together, or enough help from others to be able to hold on. Others were uncertain about holding on in the near future. Despite this uncertainty, most informal carers were satisfied with the care they provided, or said they just tried their best.

“I feel like I’m doing pretty well.” (9)

“I think he can receive no better care than from me, I can see what he needs.” (5)

The advice that informal carers would give to novice carers was to be prepared for a heavy task and suggested to share the care with others, take some time off every now and then or at least talk about it with family and friends. They would give practical advice or just chitchat about more pleasant topics than their problems.

“Read some books about informal care giving, so you know what will come at you.” (6)

3.4 Impact, feelings and experiences of informal carers related to incontinence
Compared to other aspects of care, most of the informal carers found incontinence care no problem or not really different than other types of care. It was all part of their daily tasks, and it was all heavy. They have got used to the aspects they found difficult at the beginning, such as the dirty nature, the smell and the fact that you first had to ‘cross a line’ to provide this kind of care to a partner or relative.

“You just get used to that [clean your partner and change absorbing materials]. The more often you do it, the more natural it becomes.” (7)

Several informal carers compared the changing of absorbing materials to the care for a little child. Most of them found the situation especially unpleasant for their cared-for and not for themselves. Still they said that this kind of care was not pleasant and some had feelings of shame or difficulty accepting the situation in the beginning.

“I thought that was terrible. When we visited someone and I saw he had wetted his pants, terrible. But terrible for him, that’s what bothered me.” (1)

Informal carers said that to some extend, their relationship changed due to incontinence care, because of the intimate nature of it. Most of them said that x years ago, they would never have expected to be doing this type of care.

“If someone had said to me 10 years ago that I would have to clean my husband, I would have laughed at him.” (4)

3.5 Impact, feelings and experiences of cared-for people related to incontinence

The feelings about their incontinence differed among the cared-for people. Some felt ashamed and tried to hide their incontinence. A woman felt like being the only incontinent person, despite her daughter explaining she saw it every day at her work as a nurse. The people who felt ashamed about their incontinence preferred to be assisted by others than their relative or partner. However, they also accepted in some way the fact that incontinence was a part of their life. Some informal carers pointed out that, looking back at their lives, their partner or relative considered the process of becoming continent as a very important step in life. It was difficult for them to give that up and become incontinent again.

Other cared-for people seemed to have no problems with their incontinence, but these were the people that were not really aware of their health status and the amount of help they needed or forgot about leaking accidents after a while.

Others feelings caused by factors other than incontinence are: some cared-for people felt depressive or lonely or they lost the ability to express emotions.

Some informal carers explicitly mentioned that their cared-for was happy to still be at home or need his or her carer around to feel safe, to feel loved or simply to talk to.

“But he is completely happy around here, with me in our house. We have a wonderful house.” (5)

“What’s most important in our relationship is that I’m at home, sitting next to her. The idea, the assurance that I’m next to her. (9)

Feelings of sadness or anxiety were reported but not explicitly regarding incontinence.

4. Support and Solutions

4.1 Greatest help in incontinence care

Informal carers felt quite appreciated for the care they provided, but were not always supported adequately by family, friends or formal carers. Still, the greatest help came from relatives, in the form of emotional support and practical help and formal carers, in the form of practical help.
“My brother says: “When you need me, I don’t care if it’s in the middle of the night, when you need me I’ll get in the car.”” (4)

“Someone is allocated to you as a contact person. That really helped me a lot, she explained everything and came up with ideas.” (5)

Some (older) informal carers explicitly mentioned the joy of visiting their children and grandchildren and felt emotionally supported by those visits.

“Every now and then, one of my children comes and visit us. That makes my day because I’m crazy about them, especially my grandchildren, wonderful.” (1)

Being able to do things for themselves, while someone else took care of their partner or relative, was highly appreciated by the informal carers.

“So that’s when I can go visit a friend, have a normal conversation with someone, which is pleasant.” (5)

All informal carers had found the right incontinence products for their cared for person, but for some, it took a while to find it. They would have liked some help with that.

4.2 Suggestions from informal carers of incontinent older people

Informal carers found it difficult to come up with things that would improve their situation or would make life easier to them. Most changes related to moving or adaptations in the house were already realized at the moment the interview took place, like a shower chair, an extra shower downstairs, clothes with Velcro tape, sleeping downstairs, a raised toilet, etc. Only two informal carers still needed adaptations in the house. When suggesting several options, the choices were diverse. Most carers were drawn to the idea of respite care.

“Well, [what I need is] a good sit-in for a part of the day, one afternoon.” (5)

More professional help was not really needed by most informal carers as sharing the care with friends and family would be more helpful. Some carers reported that they were not completely satisfied with the quality of care from formal carers or nurses or the amount of support from the general practitioner. The opinions on informal carer support groups were diverse. Half of the carers would visit such an initiative, but not if it would take too much effort to find it. Another helpful option would be a consumers guide to select appropriate incontinence products, because formal carers could not always provide sufficient information on this topic.
5. Description of care’s profile

The following table describes and summarizes the main demographic features of the informal carers involved in the study in The Netherlands.

<table>
<thead>
<tr>
<th>The Netherlands</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Carer’s gender</strong></td>
</tr>
<tr>
<td>Male</td>
</tr>
<tr>
<td>Female</td>
</tr>
<tr>
<td>TOTAL (=100%)</td>
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<tr>
<td><strong>Carer’s age</strong></td>
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<td>Average age of carer</td>
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<tr>
<td>&lt;=65</td>
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<tr>
<td>&gt;65</td>
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<tr>
<td>TOTAL (=100%)</td>
</tr>
<tr>
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<tr>
<td>Single, never married</td>
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<tr>
<td>Separated / divorced</td>
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<tr>
<td>Widowed</td>
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<td>TOTAL (=100%)</td>
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<tr>
<td><strong>Carer’s level of education</strong></td>
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<td>University / similar</td>
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<td>Unemployed</td>
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<td>Other</td>
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<td><strong>Relationship to person in need of care</strong></td>
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<td>Carer is wife</td>
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<tr>
<td>Carer is son</td>
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<tr>
<td>Carer is daughter</td>
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<tr>
<td>Carer is daughter-in-law</td>
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<tr>
<td>Carer is son-in-law</td>
</tr>
<tr>
<td>TOTAL(=100%)</td>
</tr>
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</table>
6. Description of cared-for person's profile

The following table describes and summarizes the main demographic features of the cared-for persons involved in the study in The Netherlands.

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<tr>
<td>Female</td>
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<tr>
<td><strong>Cared for’s age</strong></td>
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<tr>
<td><strong>Cared for’s memory and /or cognitive problems (assessed by the carer)</strong></td>
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<tr>
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<td>Low</td>
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<tr>
<td>Severe</td>
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<td>TOTAL (=100%)</td>
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</tbody>
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7. Analysis/Summary

**Participation**

In the Netherlands not enough respondents were found for this study. Several reasons were reported why people didn’t want to cooperate. They felt ashamed and did not want to discuss this subject, not even with health care providers, or did not think it was important enough. On the other hand, there were also organisations that did not want to ask their clients to cooperate. They found it too much of a burden for them. People that did cooperate said they offered some of their limited time but hoped that the study would make a difference in the support for informal carers.

**Reasons to take care**

Reasons to take care of a partner or parent were diverse, but most respondents found it natural, especially when care had become gradually more over time. They felt a sense of duty, especially when married, and explicitly referred to the wedding vow.

Apart from these reasons some informal carers reported the prevention of admission to a nursing home. Their partner or parent wanted to stay at home and they respected that wish, or they didn’t want to be alone.

Costs played no role in the decision to give care.

**Daily routine**

Informal carers living with the cared-for person stated the incontinence care was very time-consuming. But also other types of care, especially when clients could not dress, wash and feed themselves, took a lot of time. Informal carers not living with their parent did not feel like being busy all day long, like the other carers did.

**Problems**

All informal carers, except for one, had problems due to incontinence and experienced this as unpleasant. These problems were mostly related to cleaning and assisting with incontinence very frequently or at inconvenient times of the day.
Physical problems were barely reported but when informal carers had them, they were seriously burdened with tiredness or even exhaustion and back pain.

Practical problems were mostly related to formal health care: the lack of it or the quality of care. The need for constant watchfulness was also considered a problem and for the concerned carers this resulted in an irritable mood or a feeling of being too busy to do other things.

Restrictions

All informal carers living with their cared-for persons felt locked inside the house. Half of them because of incontinence problems, like assisting them to the toilet often, assisting them to the toilet at night or the client not being able to use a strange bathroom. Half of them felt locked inside due to other factors: they were physically impaired or had moved to a senior apartment and missed the activities and social life they had in their former house.

All clients and some informal carers seemed to have accepted the fact that they stayed inside most of the time and felt no desire anymore to go outside.

Informal carer’s feelings in general

There was a strong common feeling of resistance to nursing home admission, because of bad experiences during temporary admissions, stories from others, of because carers did not want to be alone. However, some felt like giving up sometimes, at moments that they experienced the care as very heavy. None had taken steps towards admission so far. (In the Netherlands, you need an indication on medical grounds before you can move to a residential or nursing home, this process can take several weeks).

The change in character and relationship had a huge impact on the informal carers. Relationships of husband and wife had become relationships of client and carer or parent and child. Partially this could be explained by the intimate nature of the incontinence care, but mostly because the character of cared-for with dementia had changed dramatically and the clients needed a great amount of care. Dementia and the consequences of stroke made the cared-for people very dependent and made them behave like children again. Carers missed the love and affection they used to have together.

Informal carers with the most intensive care had put aside their own needs and wishes and the client came in first place. This even resulted in feelings of shame in informal carers who took some time for themselves. It was not the case for carers who provided less care, they had more help from formal carers, or provided care only a couple days per week.

There was a division according to the feelings mentioned above between informal carers with positive attitudes and negative attitudes. Some carers were able to approach the situation positively, which helped them to be hopeful on the future and happy to be with their loved one. Other carers felt overburdened and could hardly see any positive aspects of giving care.

Asking help from children was difficult for informal carers. Asking help from brothers and sisters happened more often, for children as well as partner carers. Two carers mentioned that they were criticized instead of supported by family, which made caring heavier for them.

Informal carer’s feelings on incontinence

Informal carers reported all sorts of feelings. It was sometimes difficult to determine if these were related to incontinence or care in general, because incontinence was so clearly just one of the many aspects of care. Informal carers first had to cross a line to provide this type of care, so it was difficult at the beginning but they got used to it quickly, by just doing it. Feelings of shame were no longer present, they said. If they found the care unpleasant, it was especially for their partner or parent, being independent and in need of very intimate help constantly. Although nobody had a problem with providing this type of care, they almost all used words like ‘bad smell’, ‘dirty’ or ‘not pleasant to do’. They talked about incontinence accidents in detail to explain how unpleasant these situation could be and how much time it cost them to deal with that.
Care was compared to taking care of a child, which made some realise it was easy, just like cleaning a baby is easy. On the other hand, it made some realise it was not that easy, because cleaning an adult is different and more difficult than cleaning a baby.

Feelings of cared-for people

The cared-for people that realised they were incontinent felt ashamed about it or found it unpleasant for their informal carer, unpleasant they had to provide this type of care. The cared-for people who had no problems with their incontinence were people with severe dementia, who had no realisation of their own situation.

Feelings of sadness or depression were mentioned but not particularly related to incontinence.

Greatest help

The greatest help for most informal carers was practical help from formal carers. This could be advice, assistance in the daily care or the fact that the cared-for person was not alone at that moment and the informal carers could go out. Some carers also mentioned their family as being helpful, for providing care or emotional support.

Literature review

The literature review on the burden of incontinence care (Versteeg, 2010) showed that this care was more burdensome and more time-consuming than other types of informal care. Since we only interviewed informal carers providing incontinence care, we can make no statements on this matter. What we can confirm is the nature of incontinence care: it was found both in the literature and from the interviews that some cared-for people need constant watchfulness and the care has a continuous nature, which makes it burdensome. The finding that incontinence would be discrediting is not supported from the interviews. It was referred to as dirty work, but not considered as low paid work.

Carers interviewed in previous research as well as carers interviewed for this study reported role changes. Carers start to perform tasks they were not used to do or that their partner used to do. The exhaustion mentioned in the review was only seen in some of the interviewed carers. Feelings of shame were barely reported but were present when ‘reading between the lines’.

Informal carers found it hard to name helpful interventions during the interviews. When asked for, they were most drawn to the idea of respite care and also to sharing care with family members, a consumer guide to select appropriate products and attending an informal carer support group. These last two interventions were also found to be helpful from the literature.

8. Conclusions

In general, the incontinence care had a substantial impact on the informal carers daily life, but was not considered as burdensome as the changes in behaviour due to e.g. the dementia or stroke. These changes resulted in a shift from a lover’s relationship to a carer and client or parent and child relation. Although informal carers stated that the incontinence care did not bother them so much, especially compared to the cognitive impairments, they all used phrases that made clear it was sometimes really unpleasant and shameful. Despite these feelings, there was a strong resistance to nursing home admissions among cared-for people as well as among informal carers. The informal carers felt as if they did not have a choice. They would never choose for the situation they were now confronted with. But because of love, they still cared for their partner or parent with love.

Feelings on care in general were very diverse. Feelings on incontinence care on the other hand, were quite consistent. It was difficult in the beginning but informal carers had accepted it and got used to it now. It had a limited impact on family relationships, work and the financial situation. Changes in social life were reported. Some cared-for persons needed constant watchfulness because of their incontinence or it was difficult for them to use other toilets. However, changes in social life were especially due to other factors than incontinence. Couples had moved to senior apartment, had less contact with neighbours and friends, had difficulties visiting friends and family or suffered from physical impairment.
There was a great difference between the informal carers living with the cared-for person and the informal carers living apart from them. Being able to step away from the care for a while was highly appreciated but hardly possible for the informal carers living together with their partner or mother.

The most important difference between this study and the literature were the feelings of shame. They were not reported as often and as strong by the interviewed informal carers as in the literature. However, a formal carer that was involved in the recruitment of informal carers reported that some informal carers did not want to participate in the study. They were ashamed of the incontinence of their partner of relative and did not want to talk about it. Because we did not interview these people, we might have a biased view. Feelings of shame might also explain why we did not manage to find enough informal carers for the interviews.

9. Literature


ANNEX 5 National Report from The Slovak Republic

Introduction

According to epidemiological research on the availability of health care patients suffering from incontinence, 20% of women in age about 45 years are affected by easier form of incontinence. More severe forms of bladder weakness affect 15% of women and 8% of men aged 65 and older, according to Dr I. Švihra at a news conference, who supervised the research. (Incontinence, 2010). Up to 25% of women in the Slovak Republic is affected by incontinence. The lowest prevalence is in the age group 30-39 years (23,3%) and the highest in the age 80 and over (55,6%). Despite the high incidence in female population, seeking of medical assistance is low. Due to adverse social effects of this disease, many patients suffer from feelings of shame and refuse to admit that this is a problem for them (http://sk.hartmann.info/SK/brozurka_inkontinence.pdf).

1. Informal carers and cared-for-people

1.1. Recruitment

In the Slovak survey team there were two members responsible for finding suitable respondents and providing interviews with them. The geographical area, in which we were looking for suitable respondents was rather wide, and Slovak team was able to complete the sample according to established criteria. We have used various channels for looking for carers but they were usable in different measure. Two of them were the most efficient. The highest number of respondents was gathered through information from municipalities and snowball sampling. The other respondents were recruited via organisations of professional healthcare and social care workers, the rest were involved on a door-to-door basis by approaching us and offering to participate.

Except this, we also used the possibility and pay for respite services for those who required them.

1.2. Characteristics

In the Slovak Republic 17 people were interviewed, out of which 12 were women and 5 were men. Regarding the relationship to the cared for persons, 8 spouses (2 husbands and 6 wives) and 9 children (3 sons, 5 daughters and 1 daughter-in-law). 14 carers lived in the same household with the client. Two carers visit their clients in their homes daily. One carer lived in the family house with the client, with separate entrances to each flat.

A majority of carers live on retirement income (8). Two carers are self-employed subjects, one has a full-time job and one person has a part-time job. One person is unemployed and 4 persons indicated the option “other”, including contracting job (1), suspended trading (1) and care/nursing allowance (2). Working and employment status is typical mainly for younger carers, but also 2 of people who retired still work and their working time is shorter.

Family members, taking care of their relatives, have achieved various education degrees. The biggest group of carers has secondary education without graduation (6), the second biggest group is people with secondary education with graduation (5), 4 of them have higher education and 2 of them have elementary education.

All interviewed persons are the main carers of their incontinent relatives, and helped them every single day. Many of carers, mostly those who are simultaneously economic active have other helpers - mostly among other family members who substitute them when they are out of the home. Only one informal carer (husband) uses paid nursing services for the time when he is in the work.
2. The care situation

2.1. Main medical reason for care

In the Slovak Republic, the main reasons for care were stroke, gradual growing of problems, hip fracture and dementia. Many of cared-for persons were cognitively impaired due to dementia stroke or other diseases (cognitive impairment was diagnosed in 10 cases).

"My husband had a stroke and needed help, so I automatically decided to take care for him." (R3)

"I have been living with mum in the same household for many years. She’s 90 now and needs assistance so I do it for her." (R8)

“Well, I began to care for him after his first leg was amputated, which was ten years ago". (R10)

2.2. Duration of care / Modality of providing care

Informal carers have been taking care of their relatives with incontinence for different lengths of time. The shortest period of time listed in the Slovak Republic group of people being cared for was 4 months, while the longest period of time was 11 years.

<table>
<thead>
<tr>
<th>Duration</th>
<th>Who</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than 12 months</td>
<td>R2, R3, R7, R15, R17</td>
<td>5</td>
</tr>
<tr>
<td>Between 12 months and 3 years</td>
<td>R6, R11</td>
<td>2</td>
</tr>
<tr>
<td>More than 3 years</td>
<td>R1, R4, R5, R8, R9, R10, R12, R13, R14, R16</td>
<td>10</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>17</td>
</tr>
</tbody>
</table>

There were 5 carers, taking care of the relative with incontinence less than 12 months; 2 carers have been providing care for 1 - 3 years and the majority of carers have been providing care on a long-term basis, i.e. more than 3 years.

Most of the people cared for (4) for longer than 3 years suffered from stroke, 2 needed help due to hip fracture, 1 due to dementia and 3 due to a gradual escalation of problems. Among those, who are being cared less than one year there are 2 clients who need care due to stroke, 2 due to gradual growing problems and one due to hip fracture. There were only 2 clients who are being cared in interval from 1 to 3 years, one of them needs the care due to dementia and one due to gradually growing of problems.

2.3. Reasons for taking over care

There were given a few reasons for taking care for incontinent elderly family members. Each carer give more than one reason but we were able to identify 3 leading factors among them:

a) Sense of duty to take care of a parent:

“Oh, she’s my mother." (R7)

“It's my duty. As I am her daughter." (R13)
b) A marriage:

“Well, look, she is my wife. I have promised to be with her in good and bad times. So that’s it.” (R1)

“He is my husband, so it’s natural that.” (R10)

c) Preventing from placement of the relative with incontinence in a social care institution:

“I would not place him in an institution for nothing.” (R3)

“I just could not leave him in an institution just like that.” (R14)

There were also other reasons, not so frequent, and they were reported as “other reasons next to major reasons”, indicating that several reasons have influenced a decision to take care of a relative with incontinence. Among them were such as natural, financial costs along with emotional reason. One carer, taking care of her husband, experienced economic loss mainly at the beginning and the situation improved since their living-in son started earning more money after getting a new job.

“We experienced huge financial problems at the beginning.” (R9)

“My husband was already on a wheel-chair when we met. ....I was aware of what I was to expect even before the wedding.” (R6)

In one case, a sense of duty, expressed as the reason was not a natural decision, but resulted from the pressure of circumstances as the carer revealed other circumstances that forced her to become a carer.

2.4 Daily routine

Daily routine of carers of family members with incontinence depends mainly on the type of incontinence, as well as on the client’s health in general. In our group 11 carers took care of clients suffering from involuntary leakage of urine and stools, 5 clients suffered from involuntary leakage of urine and 1 client needed care due to leakage of stools. In some clients with leakage of urine, leakage of stools was observed sometimes, however, according to the carers, this was the case when the client did not make it to the toilet (including the use of a commode).

<table>
<thead>
<tr>
<th>Type of incontinence</th>
<th>Who</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Urine</td>
<td>R1, R2, R3, R4, R5, R6, R7, R8, R9, R11, R12, R13, R14, R15, R16, R17</td>
<td>16</td>
</tr>
<tr>
<td>Faecal</td>
<td>R1, R2, R3, R6, R7, R9, R10, R12, R13, R14, R16, R17</td>
<td>12</td>
</tr>
<tr>
<td>Day and night</td>
<td>R1, R2, R3, R4, R5, R6, R7, R8, R10, R11, R12, R13, R14, R15, R16, R17</td>
<td>16</td>
</tr>
</tbody>
</table>

In most cases a leakage of urine during day and night was reported and carers were not able to define at what time of the day or night it usually happened. Immobile patients, who are not able to get up from their bed neither by themselves nor with assistance, and use a toilet or a commode, experience similar situation. The carers described this situation:

“All day long. Day and night, urine and stools.” (R2)

“I don’t even know when he pees because he has a diaper, I just touch him, you know.” (R9)

Recipients of care who are able to move or to tell the carer that they need to go to the toilet, get helped (either with going to the toilet or with a commode). Some carers position their loved ones on the toilet several times a day, or they use preventive methods to save from cleaning (they try to control the stools at least).

The most reported daily routine activity of carers of family members with incontinence is cleaning and
washing the person receiving the care. The carers do the cleaning and changing of incontinence products at different places and with different frequency, depending on the client’s mobility, whether the client can either walk to the toilet/bathroom or get up from bed by himself or with the carer’s assistance. Ten carers do regular cleaning of the patient on his/her bed. They only provided a brief description.

“Everything is done on the bed, we change diapers on the bed.” (R14)

Six carers specified that they clean the patient by the bed in the patient’s bedroom. This is mainly by carers who care for patients who are able to stand up. They change incontinence products and use a commode.

Only one carer changes incontinence materials in the bathroom/toilet.

Apart from changing incontinence materials and cleaning, people who take care of their relatives with incontinence, perform many other activities during the day. The carers reported dressing and undressing the client (8), changing of underwear (8), helping the client to the toilet (6), skin care (6), and feeding of the client (5). Working around the house was often mentioned (11). It was reported by 2 men and 9 women taking care of their spouses. None of the sons had mentioned this activity. Much of their daily routine included taking care of the skin to prevent bedsores. They talked about various healing and protective creams.

When describing their daily routine, the carers made difference between “a typical day” and “an atypical day”. A typical day is considered when all activities related to changing of incontinence materials, the changing intervals, cleaning and washing, adjusting of the client, and breakfast, are not beyond the scope of everyday activities. An atypical day is a day, in which other activities interfere with their daily routine. This include more frequent changing of incontinence materials, extra cleaning and washing, preparing special meals or asking another person for help (either a professional, a friend or a family member).

“It’s hard to say what is my typical day. It often depends on what the previous day was like. Whether my husband was tired, whether he had pain…when he gets up in the morning, he is always in pain. My first task in the morning is to do the sanitation. I change his diaper …(hesitating)…it is quite difficult…not to get dirty too much.” (R6)

Carers get into a routine after repeating these activities for some time. The problems they reported mainly at the beginning when they did not know how to use the changing incontinence materials properly and how to do the washing – mainly with clients in a lying position. Those who were lucky to cooperate with care services have praised their approach and how they were instructed by them on the proper size and the use of the incontinence materials. They were also advised on how to take care of the skin to avoid bedsores. However, most of the carers had to find their own way how to do this or get information from more experienced carers.

Carers have different timing and time intervals of performed activities. For some of them the day begins early in the morning, for others much later. Those carers, who must perform some activities around the client before going to work, have indicated an early beginning of the day.

“Well, I get up at 5 or 5.30 a. m. and I start immediately. I have to change diapers, maybe even all bed linen – and this is sometimes three times a day. Then breakfast, washing and cleaning etc.” (R14)

“I get up at 5 in the morning, because I go to work. First I put my Mum on the toilet, well we use the commode, she has a diaper during the night, then I change her diaper and she washes herself, others respect the waking time of the client.” (R4)

During a typical day, most of the carers have reported the changing of incontinence materials and washing and cleaning 3 times daily. However, in some cases, the cleaning is done more often and it is considered a typical day.
Some carers, trying to avoid frequent changing of incontinence materials or washing and cleaning of the client, use a urine bottle and check the client more often, they check the diapers or help the client to go to the toilet.

“If I want to prevent washing him all the time, I have to be near him. And it goes like this until the evening. We go to bed at nine or ten and he wakes me up ten times at night. So that’s it, 24 hours all along (laughing).” (R3).

Another carer said there were no regular intervals in her care.

“Well, I don’t change the diapers regularly. No regular intervals, I just concentrate on ALWAYS checking on him. Not when he peed, you don’t have to check that all the time, because, look, you hold it here and it fills right in here. And when he does number two, you can smell it, see, I know he has stools mostly in the evening, but I am telling you the diaper changing is not regular, for example he has this diaper for two hours now.” (R11).

3 Problems

3.1 Problems encountered in incontinence care

A reply to a straight question “What problems do you experience in the caring process?” the most common reply in the Slovak Republic was:

“Oh, no problems. At first, it was.” (R7)

“No problems in our family. We got used to it.” (R14)

After regulating the interview, they talked more in details about the problems that the carers who take care of clients with incontinence experience everyday.

The problems included mostly physical issues, resulting from exhausting lifting up of the client, such as painful joints, arms, some carers indicated backbone problems etc.

“Well it is my backbone, it is ruined.” (R14)

“Well, I have problems with my backbone; mainly due to the diaper changing. I have to lift her up often. She is heavy.” (R16)

Among other problems, carers indicated problems with a client, like constant necessity to watch him/her, constipation.

“Well, it is mostly IN THE MORNING, I don’t catch his time and he pees all over.” (R11)

Another group of problems include practical problems, reported only by 3 carers. These were the cases of wrong incontinence products (mostly in the beginnings).

“First, I had SMALLER diapers and they caught SMALL CONTENTS of urine, but three months ago I found BIGGER diapers. Often urine was leaking. I had to change the mats often and to wash clothes.” (R1).

Some carers perceive their problems both as physical and emotional, one carer could not handle the situation with his mother, that he as a son had to do all the cleaning and washing of his mother and it is an emotional problem.

3.2 Impact of care on informal carer’s life
According to carers in this study, their social life had changed since taking up care of a close relative with incontinence, actually resigning to some social activities. They mostly meant activities out of their home – reported by spouses who take care of their partners.

“Look, I am limited, I have to be at home, and I have one formal carer coming to help. Since September she comes for 3 hours a day instead of previous two, because I still teach at Secondary school for nurses.” (R1)

“People say you never go anywhere, but WHERE SHOULD I GO? My job requires doing preparations at home. I come back from work, I have to take care of my mother, then cooking, and getting ready for my work in the evening.” (R4)

Children taking care of their parents reported limited activities with their colleagues and family, such as a holiday etc. This was more due to the time stress than incontinence of a client.

“So we cannot go anywhere,...we have literally not been anywhere together.” (R10)

“I have to spend more time with her, I am limited and I cannot travel.” (R8)

Only one person mentioned incontinence as a reason for limited activity.

“I am tied down, I cannot afford to go out, to talk to my neighbours, I cannot go out for long, I mean. I can do 5 -10 minutes, yes, but I cannot just stop and talk to someone in the street. I have to do my shopping and hurry on home.” (R3)

One carer indicated just partial restriction.

“We go for a walk in the afternoon so that he sleeps better at night ...we go shopping or go to visit a doctor in the morning.” (R11)

24 hours care for a client with incontinence is physically and emotionally demanding a majority of carers reported that they did not regard care as being trapped at home, on the other hand they admitted they were restricted.

“This situation befalls us A LITTLE BIT, unfortunately, that’s it, and it will not be different, but I shall stand up again and continue, there is nothing to speculate about (laughing).“ (R5)

Some carers got used to being at home because of caring, but they do not regard caring as a trap.

“No, we are used to it.” (R6)

“I have never had such feelings.....it’s normal to take care of him.” (R7)

Another carer had a different view on restrictions, because she could take her husband out for a limited time.

“Well, you can go anywhere in a diaper. Anyway, we don’t go out for long, and even if we go, we get back soon.” (R9).

In one case a daughter perceived taking care for her mother as being trapped at home.

“Yes, that’s my feeling.” (R13).

Some carers indicated feelings that care for their relative with incontinence restricts their career, but it was not because of incontinence.
“Well, yes. Because......in education process you have to continue learning, training and I keep postponing some activities. So, it is bad, like when I want to do something and I want to do it because it’s a long time until I retire but I cannot do it. And she adds: "sometimes I thought about quitting work and staying at home, but we wouldn’t manage financially. “ (R4)

“Yes, because my professional development has stopped.” (R13)

Two carers reported that they could not spend as much time at work as they would like to and they have to reduce their working time

“I have to reduce” (the number of hours spent at work), and she adds “but I MUST have the job.” (R14)

“I work three hours a day, I cannot do more, because my mother needs me.” (R16)

Although they reduced their working hours and restricted their own career due to the care for a relative with incontinence, they did not think about giving up their jobs.

Carers, who are economically active, look for various solutions. A son and his wife take turns in taking care of his mother, both having adjusted their working time. They exchange information on the mother’s condition during the day when meeting at the station. Only one daughter admitted she would give up caring and go to work.

3.3 Feelings and experience of informal carers related to caring in general

The carers described their feelings when caring for a family member with incontinence in many different ways. Most of them (11) had neutral feelings and they did perceive caring as something necessary that has to be done and they reported to have neither positive nor negative feelings.

“I don’t make any fuss about it.” (R11)

“I regard this as inevitable.” (R14)

“No problem for me. OK. I am not fragile, so I can do it (laughing).” (R3)

“That’s life.” (R1)

Some carers said that taking care of their relative was their own decision. Also puzzled feelings were recorded resulting from the care for a client with incontinence.

“I cannot say what kind of a feeling it is. It is...” (R10)

Some carers expressed they had feelings like feeling sorry for a client and his situation:

“Well, sometimes I think that I would not want someone to have to take care of me, but I cannot help. This is life. We have to accept it as it comes.” (R4)

“I keep thinking about it whether it could happen to me and I cannot deprecate or criticize but I have to come to terms with it.” (R12)

A son, caring for his mother, mentioned awkward feelings, resulting not from incontinence, but from the way he was brought up and what influenced his feelings and approach when touching intimate parts of the body of a relative.
“Feelings, well...after some time you don’t realize it any more, it must be done, so I do it, you know. At the beginning it was so strange, because I am a man. But this is my mum, it is different, I was brought up in a different way, as compared to today, I did not dare, but nobody else could do it, so I did because it must be done. I am glad that I and my wife can do it and no other strange person and...” (R15).

A daughter said that she regards caring an exhausting work.

“(sighing) ... (thinking)... Sometimes it is difficult. But I do want to help her. I help her, I love her and I do not think about it...” (R16)

Despite the fact that incontinence of a relative and care for such person has various consequences on physical health of carers and is very time consuming, the carers reported positive aspects, which represent good motivation for care.

“Just the expression of her face is rewarding for me, she looks at me and is happy how I managed it all.” (R1)

“I am so happy he is here (smiling). That I am not alone.” (R10)

“That is a motivation for me, when I see that she is happy.....that drives me forward.” (R12)

Another carer found the fact that she could take care of her mother, positive, although this statement was neither encouraging nor reliable. It is more of a duty, taken over by them due to other reasons than her own decision. However, she recalls her sense for dutifulness and although she uses neutral gender in her talk (not she, but it)

“That there is none to take care of her. That it’s only us. Would you throw her out on the street or what? (nervous voice).” (R2)

Some carers take care of their helpless relatives as something that gives them good feeling and they regard this activity as empowerment while fulfilling the protective role of a family.

“Our family has always empowered us and therefore I take the care for her for granted.” (R4)

“Do you know my motivation? My motivation is that I want to help him. And he really depends on me.” (R9)

Some carers pointed at the emotional bonds between a client and a carer, they are happy to have a relative by them.

“The most important is that I am with her. Eventually, if I would place her in a social care institution, I would probably see her once a week, when I have time. And now I see her all the time.” (R15)

“I would give her everything. Why, she belongs to us.” (R7)

People, caring for their close relatives with incontinence experience various conditions of their work. Their answers to the question on satisfaction with their performance were all positive, although there were some differences. The answers were divided into two groups. The first group included satisfaction of a carer with the provided care.

“Yes, I am satisfied (sighing).” (R3)

The second group of answers included statements that they do as best as they can.

In spite of numerous changes (in living conditions, in a job or in social life) taking care of a relative with incontinence usually did not influence the relationship between a carer and a relative being cared for.
“Our relationship was good, we have never experienced any problems, and when the situation came, we made our decision without hesitating. We decided to be with her so that she would feel well.” (R8)

“No, definitely not......she does not have any problems and neither do I.” (R12)

A wife, taking care of her husband, indicated a change in family relationships, not as a result of his incontinence but because of alcohol dependency of her husband.

“Not because of his incontinence, but due to another reason.” (R14)

One daughter indicated a change in the relationship between a mother and her; a mother did not recognize her and thought she was a stranger, and at the beginning the daughter was upset.

“It is strange now. I have put up with it, and she tells me thank you, milady (smiling). At first, I was upset and told her: Mum, I am not milady, I am your daughter.” (R7)

A change in the attitude of a client toward his wife, caring for him, was reported in one case. She admitted it was hard for her at the beginning.

“I can see now that he......(she quiets her voice down). He often cried, mainly at the beginning. So I start talking about silly things then (inarticulate talk).” (R9)

In most families, the family relationships were not influenced by care for a family member with incontinence and the carers expressed their opinion as follows:

“No, it does not influence our relationship. My children are good and they also help with everything I need. I AM SURPRISED that they are willing to come every second week.” (R1)

“No, because my children always come to help if they can.” (R10).

One carer described the stable and unchanged situation by saying that the relationship remained the same, but contacts with their children have been rare even before.

“The relationship has not changed, because they don’t visit often, they don’t come, so it could not have changed, they probably have no idea what it is like.” (R12)

“Because they only come here to visit and ask about the progress, how we are doing……..but otherwise…our relationship…..is not so close and family-like.” (R17)

In some families the relationships have changed more due to the care for a mother in general rather than due to the care for a person with incontinence.

“Well it has affected my relationship with my siblings who live abroad and they have no special interest.” (R13)

One son declared deterioration of family relationships but not with all members.

“We as a family have fallen apart. My brothers and my sisters? My eldest brother helps; our relationship is more or less good. But the others?” (R15)

One carer felt the family relationship changed due to the nervous atmosphere in the family (she takes care of her mother-in-law, living in a separate flat within one house; apart from changing incontinence products and washing and cleaning, several family members come and check on them, but they are not always willing to come)

Despite all the love and duty there were a few among the carers, who considered giving up caring.
“Frankly, I have had such thoughts. I am considered giving up since the New Year, because I myself have health problems and I must deal with them. I am exhausted.” (R13 – this will only be a temporary solution for three months, until she has dealt with her health problems);

another carer was quite straight, saying:

“Every carer has had such thoughts. It attacks each of us after some time. He/she just says I am fed up with it, yes, but......so far, it has always helped me and my wife as well, the relationship that we have, we deal with all problems together, we make coffee and sit together at the table when my mum goes to bed, and we talk about everything and always find a solution. And when we get up in the morning we are glad that mum is still here” (R15).

Some people absolutely do not admit this thought and the reason is resistance to nursing homes.

“Well if I fell ill or I could not care for him, then I would consider some place for him” (R11).

A majority of carers do not admit this option.

Several carers mentioned in their interviews that they received much help from advice and experiences of professional carers, as well as acquaintances, who have taken care of their relatives at home. Therefore our question was what kind of advice you would give a carer who is beginning to take care of a family member at home.

Based on their own experiences, their advice was mostly patience, expressed in several forms.

“Well, to be very patient (laughing). You need a lot of patience for that. Well, and, indulgence.” (R11)

“Patience......you need it in caring.“ (R12).

Following this advice, there was some practical advice:

“Well I would tell him how to use things.....what he should get, I mean what kind of aids and a good cream to prevent bedsore." (R3)

Advice on where to search for information:

“To contact a doctor especially at the beginning, to get information what he needs and how it will go on.” (R8)

and advice on how to prevent the odours in the flat.

“I would only tell him to do it........ to do it often, so that it would not smell, so that it would be, MANAGED. When you manage it, there is no problem. It is very demanding but you should manage it. Then there are no problems." (R13)

Several advice for the beginners included advice to think about the matter thoroughly, if and under what conditions one should take up care of an elderly relative with incontinence. Various advice given by carers followed, such as:

“Take a deep breath, pull up your sleeves and get to work. Care for an elderly is a difficult task but don’t be afraid. The first days are quite of a shock, one is so…I don’t know.” (R7)

“What kind of an advice (smiling)… Advice, well, advice, you should think it over. You have to give up so many things you used to do, yes. To think about it, how you are going to do it – as long as there is a couple who will take care of a father-in-law, a mother-in-law, a father, a mother. THINK IT OVER VERY THOROUGHLY and HAVE A LONG DISCUSSION ABOUT IT. To write down all the pros and cons, and any other advice.......according to my
experiences, there is nothing to be afraid of” (R15)

There was advice on sharing the burden of care

“DON’T STAY ALONE and have a companion, either a sibling or somebody else. It’s too much for one person and it is difficult to cope with it if you are alone; otherwise you start thinking about placing your mum in an institution, because the family is falling apart. You can really benefit from good family background.” (R16)

One of the advice included recommendation to find your own system of work and to try everything; to accept things with good humour; and to have in mind that you do it for your loved one and

“NOBODY ELSE would take such good care of your loved one than a family member” (R17).

3.4 Impact, feelings and experience of informal carers related to incontinence

One of the essential tasks of our study included an answer to the question what is the difference between incontinence-related care and other types of care performed by the carers. A majority of carers of relatives with incontinence does not see any difference between incontinence care and other types of care.

“I don’t perceive this differently.” (R1)

“Well, no, I don’t. I don’t have any problems with it, as I said, none problems at all. I don’t care whether she needs to do number one or number two or needs washing from this or that that absolutely does not matter. I PERSONALLY don’t find this exhausting. For me, that’s PART OF LIFE.” (R3)

One client has compared this to cooking and she does not see any difference, either.

“Well, sighing, I don’t know. It is a routine for me and I don’t have any problems with doing it. Like if I was cooking. My thinking is, it is my duty and that’s it (laughing).” (R7)

For others, incontinence-related care is physically demanding, because of the lifting involved, one carer defined incontinence-related care as time demanding and she said it was easier for her at weekends than during weekdays, because she could spend more time with her mother and she does not have to rush when taking her to the toilet and she doesn’t get anxious about being late for work. Another daughter, taking care of her mother, considers incontinence-related care more important compared to other types of care.

“It is certainly more responsible. It is anyway, it is IN MY HEAD ALL THE TIME. If she were wet, I would leave everything and first I would go and change her diaper.” (R13)

For the other one it is an effort associated with changing of incontinence products and resulting physical exercise.

“Well, caring is not a burden, just changing of diapers, she is TOO heavy and often I have to lift her up from the ground and put her on the bed, I find it quite exhausting, I have backache, it gets worse when I change her diapers... I have to be at home all the time.” (R16)

A son, taking care of his mother, considers all activities the same. However, he, as a son, expressed hesitant feelings related to incontinence. One husband has also mentioned an intimate feature, saying that taking care of intimate organs is more demanding.

“Well, there is a difference, you know, the location, either male or female, how should I say this... you have to... dry, rub, disinfect and clean everything, because if she is not washed properly, some itching or infection may come and then... if you neglect this, more severe complications would arise.” (R17)
Several carers indicated particular activities as demanding.

“I don’t know... maybe changing diapers. You know, when she did it, and you have to change everything around her, it is annoying. IT IS ANNOYING. It is...I don’t know.” (R2)

“That is the most demanding. The sanitation.” (R11)

One husband found feeding his wife the most demanding activity related to taking care (R17 – the wife suffered from severe cancer). Even facing difficult life situations are regarded with good humour by some carers. A son indicated the following feeling:

“The most difficult task is to GET ALONG WITH HER (laughing). The rest, including changing diapers, doing the laundry, cooking and so on, what she needs in her life, that is quite normal.” (R15)

3.5 Impact, feelings and experiences of cared-for people related to incontinence

Life of clients with incontinence is complicated for themselves. They are often bound to bed, dependant on help of others, which may cause unpleasant feelings, sadness, cry, and restriction in social contacts by avoiding them. The fact of how a cared for person perceives the situation may somehow have an impact on the carer. According to the answers, the biggest group of clients (8) have accepted their situation, but it was different at the beginning.

“She has accepted it now, it was more difficult at the beginning.” (R17)

“Yes. She got used to it.” (R4)

Some elderly relatives with incontinence are ashamed. Situation and life of clients with incontinence may evoke awkward feelings, sadness and cry. Their perception of their condition is important for the carer. Naturally, with many clients it is difficult to make a judgement – mainly if the incontinence results from cognitive impairment. They can feel various stages of anxiety, sadness, discomfort etc. The highest number of carers indicated (7) that their relatives are often sad and cry.

“She cries and says she is alone and how she ended up.” (R2)

“She also cries sometimes. Yes. It’s the pain maybe....otherwise....she feels anxiety…” (R14)

“Well, she is often sad.....she is upset, but we keep talking to her…” (R8)

“You know, it makes her quite nervous. She has always been doing everything herself... It is very annoying for her and she started telling me that she should already pass away, that she is fed up with it and she has strange feelings.” (R16)

“Sometimes she starts crying, that she did not want to do it, but often she does not even know that she did it. It depends whether she is emotionally present or not (bitter smile).” (R2)

One carer said her husband was anxious, but less anxious than at the beginning, you know, he is anxious, but now since I am with him all the time, he has changed a little bit, and he is coping now and this is a big progress:

“That’s because I am at home with him. And that he can be at home.” (R9)

Resulting from their diagnosis, some clients do not realize this situation.

“She does not have any feelings about it.” (R1)

4 Support and solutions
4.1 Greatest help in incontinence care

Any help from any source is welcome for the carer of a relative with incontinence. It will enable the carer a short relax, have some time for himself, for handling his own problems and duties (a visit to a doctor, dealing with administrative tasks), time for hobbies. Family members, friends, neighbours and formal carers can provide this help.

The carer is mostly helped by other family members (if there are any, or if they live close by. Some of them enumerated the relatives in detail, some talked about family help in general.

“Well, only family. Only my family, my daughters.” (R14)

“Well it is my sister, brother-in-law, nephews” (R5)

“My nephew helps, especially with my husband. He helps with lifting him up from the wheelchair and getting him to the toilet... when he is in our house... mainly with hard work – mostly outside, the neighbours help, too. They are all willing to help...” (R6)

“My friend helps. MYSELF and my friend when he is free.” (R7)

Sometimes the help is less frequent, but more intensive during the presence of other relatives in the house of a carer:

“It is like that, for example, when my daughter-in-law comes, my son comes with his wife, and they take turns every other week, they come and help.” (R1)

and he appreciates the benefit of such help, as compared to the days when she does not have such help.

However, there are cases when help in the family is rare or not available, like a childless couple, where a wife takes care of her husband. Sometimes her sister comes to help, but she is over 80 years old (R13)

“Well, I am alone, one of my relatives lives in the neighbourhood, so I have asked her to come and stay with him” (R11 the daughter lives far away, she comes to visit her parents rarely, the son has died, so I am the only one to take care of my husband).

Carers of elderly relatives with incontinence evaluated positive advice and help, which they get or used to get from formal carers. The advice may vary, like how to take care of a person with incontinence, practical activities, how to change incontinence products, how to wash and clean the client in bed etc. Paid care services are not very popular in the Slovak Republic. Only one carer stated that he uses a paid carer, however, only when he is at work.

Others, who have used to or still use the help of formal carers, find this a good way to get necessary information.

“Sometimes I meet with the physiotherapist who used to help my mum. He asks me questions about her. You know...we talk...it helps me. I ask him some questions sometimes. I ask for an advice...” (R16).

Some use this help regularly, others just from time to time, when they need it.

“Respite care, yes, when I need it.” (R12)

Carers, who had or still have a professional help, use their knowledge and practical advice. Many of them were pleased to learn certain practical skills, which have made their work easier. They have learned how to do the washing and cleaning, and how to change incontinence products etc. Some of them have learned how to prevent bedsores.

4.2 Suggestions from informal carers of incontinent older people
Carers of relatives with incontinence perform hard work due to physical effort, time, spent with a client, emotional problems etc. Their idea of things that would make their life easier was associated with things that would make washing, cleaning and sanitation simpler.

There were several answers to this question. Technical and mechanical equipment which would reduce physical effort in care of a client with incontinence, and make life easier for a client as well, dominated in the answers:

“A better bed, maybe, a wheel-chair, if she had a wheel-chair, we could take her outside so that she does not have to lie in bed ALL THE TIME” (R2);

“We should change a bathtub for a shower” (R3);

“A good positioning bed, or a bed with a handrail on one side, so that she would not roll down from the bed at night,...” (R5);

“Bath lever would be useful….in the bathtub, out of the bathtub.” (R6);

Some of them would welcome

“Well, if the aids were more available, or the bio lamp. Why is it so expensive, why can’t we borrow it? We have to borrow it from our relatives....” (R14).

Those who have made changes in their housing, or have made it either partial or full free-barrier place, or those who already have the abovementioned aids, responded that this was enough. One carer would prefer to make changes outside the flat, and she said:

“You know, I wouldn’t want to change anything here, but those stairs here, to the outside…It’s those stairs” (R9).

Finally, some of them wish to remove the disease, or directly incontinence.

“(thinking) ...only if there were some drugs against urine leakage” (R8); “....what would make it easier. I don’t think anything would. If she were healthy and could walk, that would make my life easier” (R12).

5 Description of care’s profile

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<td>Carer is son</td>
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6 Description of cared-for-persons profile

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7 Analysis

Participation

In the Slovak Republic we found respondents who were willing to participate in the study and research sample was completed according to stated criteria. Respondent were cooperative and relaxed, they were not worried by the time, as we paid respite services for them. The qualitative research study was conducted with 17 participants. In addition to our original intention to interview 17 carers, one more interview was conducted with a son taking care of his mother. In the Slovak Republic, we found that carers took over care for a relative with incontinence in different situations: the main reasons for care were a stroke (6 cases), a hip fracture (3 cases), dementia (2 cases), and a gradual build-up of problems (6 cases). The duration of care ranged between 4 months and 11 years.

Reasons for care

Three factors, leading to taking up care for an elderly relative with incontinence, dominated among Slovak carers: a sense of duty, a marriage, and not willing to place a relative in a social care institution. In reality, each carer reported more factors behind taking up care, which were interlinked and defined in one sentence, where the major factor was followed by other factors.

Daily routine

The daily routine of carers of relatives with incontinence includes multiple activities. In addition to basic activities, including changing of incontinence products, cleaning and washing of the client, cleaning the bathroom/toilet/bed, other activities were also reported, such as dressing and feeding, preparing of special diet, as well as skin care. The range of activities during the day depended on the physical and cognitive status of the client, but also on the type of incontinence. When describing a daily routine, some carers made difference between a typical day and an untypical day, based on the frequency of the cleaning and washing activities. To avoid the effort associated with frequent cleaning, some carers take the client to the toilet more often. Housework, as part of a daily routine, was reported by women but not by men, which could be explained by the fact that their wives did all the housework (all sons in the study were married and living with their spouses). Those caring for a relative with dementia also had to mind the client.

Problems
Carers of relatives with incontinence in the Slovak Republic most often reported physical problems, manifested by pain of joints, back, arms etc. This is associated with the fact that many clients are limited in their movement and the carers have to do the cleaning and washing on the client’s bed. They have to pick him/her up, turn him/her around, and these activities are very exhausting. The equipment, making the manipulation with the client easier, is not sufficient, and this was included in the list of items, which, according to the carers, would make their life easier.

Problems with the client and practical problems were mentioned less often. Problems with the client resulted from the resistance of the client to accept his/her condition and the need for using of IC products; practical problems resulted from using of wrong IC products (mainly at the beginning when carers did not have sufficient information and practical skills). Some carers regarded emotional burden as a problem, which, along with physical burden has led to the deterioration of their health, and sometimes of another family member.

Restrictions

Care for close relatives with incontinence leads to some restrictions of carers. Husbands and wives, taking care of their spouses, have described this as restriction in social activities, which they used to together with their spouses out of the house. Children, taking care of their parents, reported restrictions in various functions with their friends, colleagues and as a family. They associated these restrictions with the time stress, rather than the client’s incontinence. One carer said that incontinence restricted social activities. The younger generation (daughters and sons) felt limited in their career, and expressed that they were being held back in their professional growth or needed to cut back on their working hours. In spite of reducing their professional ambitions or working time due to the care for a relative with incontinence, they did not consider giving up either care or a job. Some carers continue to work and keep searching for appropriate solutions of the existing situation. For example, a son and his wife work in alternative times to ensure the presence of one family member at his mother’s bedside. However, one daughter admitted that she had considered giving up care.

Informal carer’s feelings in general

Taking care of a relative with incontinence is perceived differently by informal carers. The majority of carers accepted their position of taking care of an elderly relative with incontinence, along with the physical effort and emotional burden and they find positive aspects in this role. Despite the fact that care for a relative with incontinence has various consequences on carers’ physical health and causes time stress, they regard them as positive motivation. For some, to have a close person nearby is sufficient, for others it is a feeling not to be alone. Some carers have a good feeling when helping others; some regard this as a duty, resulting from the life cycle, because children should pay their parents back. There was one negative attitude – a carer took over the care because there was no other person to do it.

Although there is one dominant carer in each family, the caring is usually a matter of the whole family. Most of the families were able to adapt to the new situation where other family members help the carer either with practical issues or other forms of support. One carer reported it was her daughter who had encouraged her and helped to accept the new role. However, there were other situations, e.g. when a carer said that her daughter expressed surprise that she was doing this. Another carer said the situation had not changed and the family relationships were the same, but the contacts with their children had been rare even before. In some families the relationships changed, but due to the care for their mother in general rather than due to the incontinence of a relative. One carer defined a change in family relationships due to the nervous atmosphere in the family (her mother-in-law lives in a separate flat of their house and the family members are not always willing to go and check on her, in addition to all the cleaning and washing and changing of the IC products).
Informal carers’ feelings about incontinence

The carers described different feelings when taking care of a relative with incontinence. Most of them were neutral and said it was something that has to be done and there is nothing to think about. Some feel embarrassed, but not due to the incontinence. Sons identified their feelings resulting from their upbringing and cultural values, which have formed their attitude towards the touching of intimate parts of the body of a relative. One carer expressed her feelings as awkward because it was not her mother who she cared for. Some carers perceived the incontinence-related care different from other types of care mainly due to the time factor, like in situations when a carer helps a client to go to the toilet and he/she has to wait until it is all finished and cannot rush him up, or the cleaning has to be done when there is time for it, and one carer mentioned that she could not accept the thought that he mother is in wet diapers.

Problems with adapting to the care of a person with incontinence were admitted by several carers at the beginning of taking up care. They resulted from a lack of sufficient information, absence of skills needed for changing of incontinence products, and cleaning. Some carers had to find out by themselves what kind and size of products and absorbing function they should use, and how they should do the cleaning and washing of the client. Those who were lucky to get help by formal carers said it was a significant source of support. Some of them still consult them in case of any problems emerging.

Feelings of cared-for persons

How people with incontinence perceive their incontinence is an important condition of fulfilling the caring role. They can either make their work easier or more complicated. Some carers were not able to describe what feelings their clients have about their condition (mainly if incontinence is due to cognitive problems). Others have described these feelings as depression, sadness, cry, anxiousness, irritability etc. Some clients are being sedated. According to the provided information, most of the clients who do not have any cognitive problems with their situation, have accepted their condition, some do not realize their situation due to cognitive problems.

Greatest help

Any help from any source is welcome for the carer of a relative with incontinence. It will enable the carer a short relax, have some time for himself, for handling his own problems and duties (a visit to a doctor, dealing with administrative tasks), time for hobbies. This help is most often provided for either by close or distant family members (children, a husband, a nephew, siblings and their partners). They regard help from other family members as very important. Two carers, who have no siblings or any close family relatives, expressed concerns about the future of care for their relative. Carers of elderly relatives with incontinence evaluated all advice and support which they have received/receive from formal carers positively. The help included advice on how to take care of a person with incontinence, with practical issues like changing of IC products, cleaning a client on his/her bed etc. Paid caring services are very rarely used in the Slovak Republic.

Literature review

As the literature review showed there are not much surveys on the problems of informal carers of incontinent relatives in Europe. In the Slovak Republic, such issues were surveyed first time. As the collected data showed, care for older incontinent relative was both physically and emotionally burdensome for carers and these findings are consistent with the literature review. For some carers is caring also time challenging as it was found in the literature. Regardless of effort expended for incontinent relative, carers refuse placing relative in nursing facilities. Collected data also showed that informal carers of incontinent relatives had to give up their social life, although the cause may not be just the incontinence.

The extra burden was felt by younger carers who are financially active and need to balance duties as a carer with family. Some carers feel total responsibility for the incontinent person.
8. Conclusions

More severe forms of bladder weakness affects about 15% of women and 8% of men aged 65 and over. Some of them also suffer from faecal incontinence. As we found in our study in many cases they suffer both from serious diseases and oft from physical and/or cognitive impairment. Because of that condition they need help on daily bases due to incontinence and family members are mostly those who give them necessary care.

Our findings showed that caring has a serious impact on family members acting as carers and its impacts are mostly felt in their physical and mental health. These findings are similar to the findings in the literature. For some of them this caring is also time consuming, as the literature showed.

Our findings also showed that carers who take care for relatives with cognitive impairment (mostly dementia) have to constantly pay attention throughout the day.

We found that most frequent reasons for taking care for incontinent relatives were love, duty and unwillingness to place him/her into a nursing care facility. Instead of difficult work they provide for them many of them are able to find positive aspects of caring that motivate them in their in caring.

Our data showed that most carers accept incontinence of their relatives, they take it as a part of life and don’t take it as a dirty work. Incontinence is not the problem that they decide place him/her in the nursing facility.

Problems with taking care of incontinent relatives was reported mostly at the beginning when carers didn’t possess the adequate skills, knowledge, information about the appropriate absorbent products and did not know where ask for the help.

Family carers are very valuable source of caring generally and they themselves often need help of various kinds. Slovak data revealed that carers would welcome technical devices that would help them to overcome the physical burden, mostly when lifting the incontinent relative.

The interview setting

The interviews were conducted in a relaxed atmosphere. On most issues respondents talked openly and honestly. Most of the interviewers described their caring activities in detail and welcomed the interest of researches in problems they encounter in everyday life.

Among the respondents there were a few who were puzzled when they should talk about incontinence. These problems we noticed among the sons who care for their mothers. In answering some questions they used non-personal expressions like “it is being prepared”, “it is being done” and so on. They also openly admitted the problems when providing incontinent care for their mothers and described it as: “you know I am a son”, “I am a man and it is different compare to daughter”.

One carer did not want to talk about incontinence care and preferred more general terminology as “hygiene” and said: “these things are between me and my husband”. The negative attitudes towards the caring for elderly relatives were identified in one case and this respondent often used the word “UNPLEASANT” which she also highlighted non-verbally. Her answers were short, often only one-word answers.
References


Inkontinencia je stále tabu. Zdravotnícke noviny, 27.5.2010, č. 21, s.2 mil.


ANNEX 6 Tables of data as outcome of the 48 interviews

**Table 1: Daily routine: types of care performed at least daily / weekly (more than one answer possible)**

<table>
<thead>
<tr>
<th></th>
<th>Italy</th>
<th>Slovakia</th>
<th>Sweden</th>
<th>The Netherlands</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Intimate hygiene</strong></td>
<td>13 (100%)</td>
<td>17 (100%)</td>
<td>4 (44%)</td>
<td>8 (89%)</td>
<td>42 (95%)</td>
</tr>
<tr>
<td><strong>Physical care</strong></td>
<td>13 (100%)</td>
<td>16 (94%)</td>
<td>7 (78%)</td>
<td>6 (67%)</td>
<td>42 (95%)</td>
</tr>
<tr>
<td><strong>Domestic</strong></td>
<td>12 (92%)</td>
<td>17 (100%)</td>
<td>9 (100%)</td>
<td>9 (100%)</td>
<td>47 (98%)</td>
</tr>
<tr>
<td><strong>Emotional/psychological/social support</strong></td>
<td>13 (100%)</td>
<td>17 (100%)</td>
<td>8 (89%)</td>
<td>9 (100%)</td>
<td>47 (98%)</td>
</tr>
<tr>
<td><strong>Mobility in the home environment</strong></td>
<td>12 (92%)</td>
<td>12 (71%)</td>
<td>2 (22%)</td>
<td>5 (56%)</td>
<td>31 (65%)</td>
</tr>
<tr>
<td><strong>Transport outside home</strong></td>
<td>5 (39%)</td>
<td>6 (35%)</td>
<td>5 (56%)</td>
<td>7 (78%)</td>
<td>23 (48%)</td>
</tr>
<tr>
<td><strong>Organising and managing care</strong></td>
<td>13 (100%)</td>
<td>8 (47%)</td>
<td>9 (100%)</td>
<td>5 (56%)</td>
<td>35 (73%)</td>
</tr>
<tr>
<td><strong>Dozing and using drugs</strong></td>
<td>11 (85%)</td>
<td>17 (100%)</td>
<td>7 (78%)</td>
<td>5 (56%)</td>
<td>40 (83%)</td>
</tr>
<tr>
<td><strong>TOTAL (≥100%)</strong></td>
<td>13</td>
<td>17</td>
<td>9</td>
<td>9</td>
<td>48</td>
</tr>
</tbody>
</table>

**Table 2: Daily routine: frequency of care (more than one answer possible)**

<table>
<thead>
<tr>
<th></th>
<th>Italy</th>
<th>Slovakia</th>
<th>Sweden</th>
<th>The Netherlands</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Daily incontinence care</strong></td>
<td>10 (77%)</td>
<td>16 (94%)</td>
<td>3 (33%)</td>
<td>7 (78%)</td>
<td>36 (75%)</td>
</tr>
<tr>
<td><strong>Weekly incontinence care</strong></td>
<td>3 (23%)</td>
<td>1 (6%)</td>
<td>1 (11%)</td>
<td>1 (11%)</td>
<td>6 (13%)</td>
</tr>
<tr>
<td><strong>Daily other physical care</strong></td>
<td>12 (92%)</td>
<td>16 (94.1%)</td>
<td>4 (44%)</td>
<td>3 (33%)</td>
<td>35 (73%)</td>
</tr>
<tr>
<td><strong>Weekly other physical care</strong></td>
<td>1 (8%)</td>
<td>0</td>
<td>3 (33%)</td>
<td>3 (33%)</td>
<td>7 (15%)</td>
</tr>
<tr>
<td><strong>TOTAL (≥100%)</strong></td>
<td>13</td>
<td>17</td>
<td>9</td>
<td>9</td>
<td>48</td>
</tr>
<tr>
<td>Table 3: Cared for person’s behavioural problems: amount (assessed by the carer)⁷</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>---------------------------------------------------</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Italy</strong></td>
<td><strong>Slovakia</strong></td>
<td><strong>Sweden</strong></td>
<td><strong>The Netherlands</strong></td>
<td><strong>TOTAL</strong></td>
<td></td>
</tr>
<tr>
<td>----------------</td>
<td>--------------</td>
<td>------------</td>
<td>---------------------</td>
<td>----------</td>
<td></td>
</tr>
<tr>
<td>No. with no behavioural problems</td>
<td>3 (23%)</td>
<td>6 (35%)</td>
<td>7 (78%)</td>
<td>2 (22%)</td>
<td>18 (38%)</td>
</tr>
<tr>
<td>No. with 1 type of behavioural problems</td>
<td>5 (39%)</td>
<td>7 (41%)</td>
<td>1 (11%)</td>
<td>1 (11%)</td>
<td>14 (29%)</td>
</tr>
<tr>
<td>No. with 2 types of behavioural problems</td>
<td>4 (31%)</td>
<td>3 (18%)</td>
<td>1 (11%)</td>
<td>5 (56%)</td>
<td>13 (27%)</td>
</tr>
<tr>
<td>No. with 3 types of behavioural problems</td>
<td>1 (8%)</td>
<td>1 (6%)</td>
<td>0</td>
<td>1 (11%)</td>
<td>3 (6%)</td>
</tr>
<tr>
<td>TOTAL (=100%)</td>
<td>13</td>
<td>17</td>
<td>9</td>
<td>9</td>
<td>48</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Table 4: Cared for person’s behavioural problems: type (assessed by the carer) (more than one answer possible)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Italy</strong></td>
</tr>
<tr>
<td>----------------</td>
</tr>
<tr>
<td>Wandering in or outside the home environment</td>
</tr>
<tr>
<td>Difficulty with normal conversation</td>
</tr>
<tr>
<td>Upsetting behaviour</td>
</tr>
<tr>
<td>TOTAL (=100%)</td>
</tr>
</tbody>
</table>

---

⁷ Examples of behaviour problems that we presented to the carers were:

- Wandering in or outside the home environment or behaving in a way that endangers their safety?

- Have difficulty holding normal conversation, have no insight into their problems, or become uncooperative with your requests

- Behave in ways that you find upsetting. For example constantly asking questions, following you around, repeating what has been said, shout and scream for no particular reason or inappropriately dressed or in a state of undress.
### Table 5: Incontinence products (more than one answer possible)

<table>
<thead>
<tr>
<th></th>
<th>Italy</th>
<th>Slovakia</th>
<th>Sweden</th>
<th>The Netherlands</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Protective pants</td>
<td>5 (38.5%)</td>
<td>3 (18%)</td>
<td>3 (33%)</td>
<td>7 (78%)</td>
<td>18 (38%)</td>
</tr>
<tr>
<td>Briefs</td>
<td>9 (69%)</td>
<td>8 (47%)</td>
<td>1 (11%)</td>
<td>2 (22%)</td>
<td>20 (42%)</td>
</tr>
<tr>
<td>Belted briefs</td>
<td>0</td>
<td>3 (18%)</td>
<td>0</td>
<td>0</td>
<td>3 (6%)</td>
</tr>
<tr>
<td>Pads</td>
<td>8 (62%)</td>
<td>2 (12%)</td>
<td>6 (67%)</td>
<td>3 (33%)</td>
<td>19 (40%)</td>
</tr>
<tr>
<td>Under pads</td>
<td>4 (31%)</td>
<td>13 (77%)</td>
<td>6 (67%)</td>
<td>7 (78%)</td>
<td>30 (63%)</td>
</tr>
<tr>
<td>Bed pan</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Male urinal</td>
<td>0</td>
<td>3 (18%)</td>
<td>4 (44%)</td>
<td>2 (22%)</td>
<td>9 (19%)</td>
</tr>
<tr>
<td>Female urinal</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Commode</td>
<td>0</td>
<td>5 (29%)</td>
<td>4 (44%)</td>
<td>1 (11%)</td>
<td>10 (21%)</td>
</tr>
<tr>
<td>Bath chair</td>
<td>0</td>
<td>5 (29%)</td>
<td>1 (11%)</td>
<td>1 (11%)</td>
<td>7 (15%)</td>
</tr>
<tr>
<td>Shower chair</td>
<td>0</td>
<td>2 (12%)</td>
<td>8 (89%)</td>
<td>5 (56%)</td>
<td>15 (31%)</td>
</tr>
<tr>
<td>Armrest on the toilet</td>
<td>0</td>
<td>2 (12%)</td>
<td>3 (33%)</td>
<td>2 (22%)</td>
<td>7 (15%)</td>
</tr>
<tr>
<td>Cane</td>
<td>0</td>
<td>0</td>
<td>7 (78%)</td>
<td>3 (33.3%)</td>
<td>10 (21%)</td>
</tr>
<tr>
<td>Walking frame</td>
<td>1 (8%)</td>
<td>0</td>
<td>4 (44%)</td>
<td>4 (44%)</td>
<td>9 (19%)</td>
</tr>
<tr>
<td>Lifting hoist</td>
<td>1 (8%)</td>
<td>1 (6%)</td>
<td>0</td>
<td>2 (22%)</td>
<td>4 (8%)</td>
</tr>
<tr>
<td>Ceiling lift</td>
<td>0</td>
<td>0</td>
<td>1 (11%)</td>
<td>0</td>
<td>1 (2%)</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>13</strong></td>
<td><strong>17</strong></td>
<td><strong>9</strong></td>
<td><strong>9</strong></td>
<td><strong>48</strong></td>
</tr>
</tbody>
</table>

### Table 6: Formal support (more than one answer possible)

<table>
<thead>
<tr>
<th></th>
<th>Italy</th>
<th>Slovakia</th>
<th>Sweden</th>
<th>The Netherlands</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>General practitioner</td>
<td>12 (92%)</td>
<td>15 (88%)</td>
<td>3 (33%)</td>
<td>3 (33%)</td>
<td>33 (69%)</td>
</tr>
<tr>
<td>Medical specialist</td>
<td>6 (46%)</td>
<td>12 (71%)</td>
<td>3 (33%)</td>
<td>3 (33%)</td>
<td>24 (50%)</td>
</tr>
<tr>
<td>Nurse</td>
<td>0</td>
<td>5 (29%)</td>
<td>8 (89%)</td>
<td>8 (89%)</td>
<td>21 (44%)</td>
</tr>
<tr>
<td>Helper or care assistant</td>
<td>2 (15%)</td>
<td>1 (6%)</td>
<td>5 (56%)</td>
<td>8 (89%)</td>
<td>16 (33%)</td>
</tr>
<tr>
<td>Occupational therapist</td>
<td>2 (15%)</td>
<td>1 (6%)</td>
<td>2 (22%)</td>
<td>0</td>
<td>5 (10%)</td>
</tr>
<tr>
<td>Social worker</td>
<td>0</td>
<td>3 (18%)</td>
<td>3 (33%)</td>
<td>1 (11%)</td>
<td>7 (15%)</td>
</tr>
<tr>
<td>Counsellor</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Voluntary worker (private) Care worker</td>
<td>0</td>
<td>2 (12%)</td>
<td>0</td>
<td>3 (33%)</td>
<td>5 (10%)</td>
</tr>
<tr>
<td>Physical therapist</td>
<td>5 (39%)</td>
<td>2 (12%)</td>
<td>0</td>
<td>7 (78%)</td>
<td>14 (29%)</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>13</strong></td>
<td><strong>17</strong></td>
<td><strong>9</strong></td>
<td><strong>9</strong></td>
<td><strong>48</strong></td>
</tr>
</tbody>
</table>
Table 7: Informal support at least daily / weekly (more than one answer possible)

<table>
<thead>
<tr>
<th></th>
<th>Italy</th>
<th>Slovakia</th>
<th>Sweden</th>
<th>The Netherlands</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intimate hygiene</td>
<td>4 (31%)</td>
<td>5 (29%)</td>
<td>3 (33%)</td>
<td>1 (11%)</td>
<td>13 (27%)</td>
</tr>
<tr>
<td>Physical care</td>
<td>4 (31%)</td>
<td>10 (59%)</td>
<td>3 (33%)</td>
<td>2 (22%)</td>
<td>19 (40%)</td>
</tr>
<tr>
<td>Domestic</td>
<td>3 (23%)</td>
<td>10 (59%)</td>
<td>0</td>
<td>2 (22%)</td>
<td>15 (31%)</td>
</tr>
<tr>
<td>Emotional/psychological/ social support</td>
<td>3 (23%)</td>
<td>12 (71%)</td>
<td>0</td>
<td>6 (67%)</td>
<td>21 (44%)</td>
</tr>
<tr>
<td>Mobility in the home environment</td>
<td>3 (23%)</td>
<td>5 (29%)</td>
<td>1 (11%)</td>
<td>0</td>
<td>9 (19%)</td>
</tr>
<tr>
<td>Transport outside home</td>
<td>1 (8%)</td>
<td>2 (12%)</td>
<td>1 (11%)</td>
<td>1 (11%)</td>
<td>5 (10%)</td>
</tr>
<tr>
<td>Organising and managing care</td>
<td>0</td>
<td>0</td>
<td>1 (11%)</td>
<td>1 (11%)</td>
<td>2 (4%)</td>
</tr>
<tr>
<td>Dozing and using drugs</td>
<td>2 (15%)</td>
<td>5 (29%)</td>
<td>0</td>
<td>0</td>
<td>7 (15%)</td>
</tr>
<tr>
<td>TOTAL (=100%)</td>
<td>13</td>
<td>17</td>
<td>9</td>
<td>9</td>
<td>48</td>
</tr>
</tbody>
</table>

Table 8: What would make life easier for the carer? (more than one answer possible)

<table>
<thead>
<tr>
<th></th>
<th>Italy</th>
<th>Slovakia</th>
<th>Sweden</th>
<th>The Netherlands</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advice from care professionals</td>
<td>4 (33%)</td>
<td>7 (41%)</td>
<td>0</td>
<td>2 (22%)</td>
<td>13 (28%)</td>
</tr>
<tr>
<td>Accessible information (types of help/support)</td>
<td>2 (17%)</td>
<td>10 (59%)</td>
<td>1 (11%)</td>
<td>2 (22%)</td>
<td>15 (32%)</td>
</tr>
<tr>
<td>Consumer guides for incontinence products</td>
<td>3 (25%)</td>
<td>12 (71%)</td>
<td>0</td>
<td>4 (44%)</td>
<td>19 (40%)</td>
</tr>
<tr>
<td>More effective incontinence products</td>
<td>1 (8%)</td>
<td>8 (47%)</td>
<td>0</td>
<td>0</td>
<td>9 (19%)</td>
</tr>
<tr>
<td>Training and education in incontinence care</td>
<td>4 (33%)</td>
<td>7 (41%)</td>
<td>0</td>
<td>1 (11%)</td>
<td>12 (25%)</td>
</tr>
<tr>
<td>Carer support group</td>
<td>1 (8%)</td>
<td>5 (29%)</td>
<td>0</td>
<td>4 (44%)</td>
<td>10 (21%)</td>
</tr>
<tr>
<td>Aids and home adaptations</td>
<td>2 (17%)</td>
<td>11 (65%)</td>
<td>0</td>
<td>2 (22%)</td>
<td>15 (32%)</td>
</tr>
<tr>
<td>Respite care</td>
<td>1 (8%)</td>
<td>12 (71%)</td>
<td>6 (67%)</td>
<td>7 (78%)</td>
<td>25 (55%)</td>
</tr>
<tr>
<td>More practical regular help from formal carers</td>
<td>3 (25%)</td>
<td>4 (24%)</td>
<td>5 (56%)</td>
<td>2 (22%)</td>
<td>14 (30%)</td>
</tr>
<tr>
<td>Sharing care with family</td>
<td>2 (17%)</td>
<td>5 (29%)</td>
<td>0</td>
<td>4 (44%)</td>
<td>11 (23%)</td>
</tr>
<tr>
<td>Help with planning of future care</td>
<td>0</td>
<td>2 (12%)</td>
<td>4 (44%)</td>
<td>1 (11%)</td>
<td>7 (15%)</td>
</tr>
<tr>
<td>More money</td>
<td>2 (17%)</td>
<td>11 (65%)</td>
<td>0</td>
<td>2 (22%)</td>
<td>15 (32%)</td>
</tr>
<tr>
<td>TOTAL (=100%)</td>
<td>12</td>
<td>17</td>
<td>9</td>
<td>9</td>
<td>47&lt;sup&gt;8&lt;/sup&gt;</td>
</tr>
</tbody>
</table>

<sup>8</sup> One missing value (Italy). That’s the reason why to total is 47 in stead of 48.
### Table 9: Carer’s gender

<table>
<thead>
<tr>
<th>Country</th>
<th>Italy</th>
<th>Slovakia</th>
<th>Sweden</th>
<th>The Netherlands</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>0</td>
<td>5 (30%)</td>
<td>1 (20%)</td>
<td>3 (33%)</td>
<td>9 (19%)</td>
</tr>
<tr>
<td>Female</td>
<td>13 (100%)</td>
<td>12 (70%)</td>
<td>8 (80%)</td>
<td>6 (67%)</td>
<td>39 (81%)</td>
</tr>
<tr>
<td>TOTAL(=100%)</td>
<td>13</td>
<td>17</td>
<td>9</td>
<td>9</td>
<td>48</td>
</tr>
</tbody>
</table>

### Table 10: Carer’s age

<table>
<thead>
<tr>
<th>Country</th>
<th>Italy</th>
<th>Slovakia</th>
<th>Sweden</th>
<th>The Netherlands</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean</td>
<td>57.0</td>
<td>59.1</td>
<td>77.6</td>
<td>66.7</td>
<td>63.7</td>
</tr>
<tr>
<td>&lt;=65</td>
<td>1 (8%)</td>
<td>11 (65%)</td>
<td>1 (11%)</td>
<td>4 (44%)</td>
<td>27 (48%)</td>
</tr>
<tr>
<td>&gt;65</td>
<td>10 (77%)</td>
<td>6 (35%)</td>
<td>8 (89%)</td>
<td>5 (56%)</td>
<td>29 (52%)</td>
</tr>
<tr>
<td>TOTAL(=100%)</td>
<td>11</td>
<td>17</td>
<td>9</td>
<td>9</td>
<td>46</td>
</tr>
</tbody>
</table>

### Table 11: Carer’s marital status

<table>
<thead>
<tr>
<th>Country</th>
<th>Italy</th>
<th>Slovakia</th>
<th>Sweden</th>
<th>The Netherlands</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Married or living together</td>
<td>12 (92%)</td>
<td>14 (82%)</td>
<td>8 (89%)</td>
<td>8 (89%)</td>
<td>42 (88%)</td>
</tr>
<tr>
<td>Intimate relationship</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Single, never married</td>
<td>0</td>
<td>1 (9%)</td>
<td>1 (11%)</td>
<td>1 (11%)</td>
<td>3 (6%)</td>
</tr>
<tr>
<td>Separated / divorced</td>
<td>0</td>
<td>2 (12%)</td>
<td>0</td>
<td>0</td>
<td>2 (4%)</td>
</tr>
<tr>
<td>Widowed</td>
<td>1 (8%)</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1 (2%)</td>
</tr>
<tr>
<td>TOTAL(=100%)</td>
<td>13</td>
<td>17</td>
<td>9</td>
<td>9</td>
<td>48</td>
</tr>
</tbody>
</table>

---

9 Two missing values (Italy). That’s the reason why to total is 46 in stead of 48.
### Table 12: Carer's level of education

<table>
<thead>
<tr>
<th>Education Level</th>
<th>Italy</th>
<th>Slovakia</th>
<th>Sweden</th>
<th>The Netherlands</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cannot read nor write</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Less than primary school</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Primary school / similar</td>
<td>3 (23%)</td>
<td>2 (12%)</td>
<td>6 (67%)</td>
<td>1 (11%)</td>
<td>12 (25%)</td>
</tr>
<tr>
<td>Secondary school / middle or high school</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Lower secondary education</td>
<td>4 (31%)</td>
<td>6 (35%)</td>
<td>0</td>
<td>0</td>
<td>10 (21%)</td>
</tr>
<tr>
<td>Secondary education</td>
<td>3 (23%)</td>
<td>5 (29%)</td>
<td>0</td>
<td>0</td>
<td>8 (17%)</td>
</tr>
<tr>
<td>Vocational education</td>
<td>1 (8%)</td>
<td>0</td>
<td>1 (11%)</td>
<td>7 (78%)</td>
<td>9 (19%)</td>
</tr>
<tr>
<td>University / similar</td>
<td>2 (15%)</td>
<td>4 (24%)</td>
<td>2 (22%)</td>
<td>1 (11%)</td>
<td>9 (19%)</td>
</tr>
<tr>
<td>TOTAL (=100%)</td>
<td>13</td>
<td>17</td>
<td>9</td>
<td>9</td>
<td>48</td>
</tr>
</tbody>
</table>

### Table 13: Carer's employment status

<table>
<thead>
<tr>
<th>Employment Status</th>
<th>Italy</th>
<th>Slovakia</th>
<th>Sweden</th>
<th>The Netherlands</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employed (full time)</td>
<td>4 (31%)</td>
<td>1 (6%)</td>
<td>0</td>
<td>0</td>
<td>5 (10%)</td>
</tr>
<tr>
<td>Employed (part time)</td>
<td>0</td>
<td>1 (6%)</td>
<td>0</td>
<td>4 (44%)</td>
<td>5 (10%)</td>
</tr>
<tr>
<td>Self employed</td>
<td>1 (8%)</td>
<td>2 (12%)</td>
<td>0</td>
<td>0</td>
<td>3 (7%)</td>
</tr>
<tr>
<td>Housewife/househusband</td>
<td>2 (15%)</td>
<td>0</td>
<td>0</td>
<td>2 (22%)</td>
<td>4 (9%)</td>
</tr>
<tr>
<td>Retired</td>
<td>3 (23%)</td>
<td>8 (47%)</td>
<td>9 (100%)</td>
<td>3 (33%)</td>
<td>23 (48%)</td>
</tr>
<tr>
<td>Volunteer worker</td>
<td>1 (8%)</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1 (2%)</td>
</tr>
<tr>
<td>Unemployed</td>
<td>1 (8%)</td>
<td>1 (6%)</td>
<td>0</td>
<td>0</td>
<td>2 (4%)</td>
</tr>
<tr>
<td>Other</td>
<td>1 (8%)</td>
<td>4 (24%)</td>
<td>0</td>
<td>0</td>
<td>5 (10%)</td>
</tr>
<tr>
<td>TOTAL (=100%)</td>
<td>13</td>
<td>17</td>
<td>9</td>
<td>9</td>
<td>48 (100%)</td>
</tr>
</tbody>
</table>

### Table 14: Relationship to person in need of care

<table>
<thead>
<tr>
<th>Relationship</th>
<th>Italy</th>
<th>Slovakia</th>
<th>Sweden</th>
<th>The Netherlands</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carer is husband</td>
<td>0</td>
<td>2 (12%)</td>
<td>1 (11%)</td>
<td>2 (22%)</td>
<td>5 (10%)</td>
</tr>
<tr>
<td>Carer is wife</td>
<td>1 (8%)</td>
<td>6 (35%)</td>
<td>7 (78%)</td>
<td>4 (44%)</td>
<td>18 (38%)</td>
</tr>
<tr>
<td>Carer is son</td>
<td>0</td>
<td>3 (18%)</td>
<td>0</td>
<td>1 (11%)</td>
<td>4 (8%)</td>
</tr>
<tr>
<td>Carer is daughter</td>
<td>12 (92%)</td>
<td>5 (29%)</td>
<td>1 (11%)</td>
<td>2 (22%)</td>
<td>30 (63%)</td>
</tr>
<tr>
<td>Carer is daughter-in-law</td>
<td>0</td>
<td>1 (6%)</td>
<td>0</td>
<td>0</td>
<td>1 (2%)</td>
</tr>
<tr>
<td>Carer is son-in-law</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>TOTAL (=100%)</td>
<td>13</td>
<td>17</td>
<td>9</td>
<td>9</td>
<td>48</td>
</tr>
</tbody>
</table>
### Table 15: Cared for person’s gender

<table>
<thead>
<tr>
<th>Gender</th>
<th>Italy</th>
<th>Slovakia</th>
<th>Sweden</th>
<th>The Netherlands</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>3 (23%)</td>
<td>6 (35%)</td>
<td>8 (89%)</td>
<td>4 (44%)</td>
<td>21 (44%)</td>
</tr>
<tr>
<td>Female</td>
<td>10 (77%)</td>
<td>11 (65%)</td>
<td>1 (11%)</td>
<td>5 (56%)</td>
<td>27 (56%)</td>
</tr>
<tr>
<td>TOTAL</td>
<td>13</td>
<td>17</td>
<td>9</td>
<td>9</td>
<td>48</td>
</tr>
</tbody>
</table>

### Table 16: Cared for person’s age

<table>
<thead>
<tr>
<th>Age</th>
<th>Italy</th>
<th>Slovakia</th>
<th>Sweden</th>
<th>The Netherlands</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean</td>
<td>83.7</td>
<td>76.9</td>
<td>83.8</td>
<td>80.2</td>
<td>80.6</td>
</tr>
<tr>
<td>&lt;75</td>
<td>2 (17%)</td>
<td>9 (53%)</td>
<td>1 (11%)</td>
<td>3 (33%)</td>
<td>15 (32%)</td>
</tr>
<tr>
<td>&gt;75</td>
<td>10 (83%)</td>
<td>8 (47%)</td>
<td>8 (89%)</td>
<td>6 (67%)</td>
<td>32 (68%)</td>
</tr>
<tr>
<td>TOTAL</td>
<td>12</td>
<td>17</td>
<td>9</td>
<td>9</td>
<td>47 10</td>
</tr>
</tbody>
</table>

### Table 17: Cared for person’s memory and /or cognitive problems (assessed by the carer)

<table>
<thead>
<tr>
<th>Severity</th>
<th>Italy</th>
<th>Slovakia</th>
<th>Sweden</th>
<th>The Netherlands</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Absent</td>
<td>3 (23%)</td>
<td>2 (12%)</td>
<td>5 (56%)</td>
<td>0</td>
<td>10 (21%)</td>
</tr>
<tr>
<td>Low</td>
<td>2 (15%)</td>
<td>6 (35%)</td>
<td>2 (22%)</td>
<td>1 (11%)</td>
<td>11 (23%)</td>
</tr>
<tr>
<td>Severe</td>
<td>8 (62%)</td>
<td>9 (53%)</td>
<td>2 (22%)</td>
<td>8 (89%)</td>
<td>27 (56%)</td>
</tr>
<tr>
<td>TOTAL</td>
<td>13</td>
<td>17</td>
<td>9</td>
<td>9</td>
<td>48 (100%)</td>
</tr>
</tbody>
</table>

---

10 One missing values (Italy). That’s the reason why the total is 47 instead of 48.
ANNEX 7 TOPIC-GUIDE

PRE INTERVIEW

Introduction at the first contact with the potential interviewee, by either the interviewer or the contact persons belonging to associations or care professionals helping with the selection:

- Briefly outline the aim of the project and introduce its topic. Since there has not been a lot of research carried out in Europe in the area of incontinence care that has actually focused on the direct experiences of carers, we’d very much like to hear the views and experiences of carers themselves, which is why you are being asked to take part in an interview. We would like to know what are the difficulties you encounter and the strategies you use when giving care to a disabled older family member affected by incontinence. We want to explore how your quality of life is affected by this caregiving situation, with a particular emphasis on incontinence care. Finally, we’d like to hear your suggestions and ideas about how we can make your current situation with regards to incontinence care better both for yourself and for your relative.

- Clarify the inclusion criteria in the sample. We wish to interview the spouse/partner, adult child or in-laws (18+) of a person aged 65 or more who needs regular help, at least on a daily basis, by a family member for managing urinary/faecal leakages. The carer we are looking for is the one who is most involved in giving this type of care and the cared for person has other physical and/or cognitive impairments.

- Reassure. The information obtained in this interview will be treated confidentially and your name and any details that may reveal your identity will not be included in any publication arising from the results of this study.

- Explain. The interview will take no longer than an hour and a half of the carer’s time and with the interviewee’s permission we would like to tape record the meeting to ensure that we have a full and accurate record of the interview that takes place for data analysis purposes.

- Reminder. During the first contact or during the interview, the name of the older person (q. 8) or their relationship to the carer (q.7) might be used in place of the
following terms which are included in some of the questions: ‘your relative’, ‘the
cared for person’, ‘your loved one’, ‘your family member’, etc.

*If they still want to participate, fill in the following:*

<table>
<thead>
<tr>
<th>Screening questions for first contact with the carer</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Univocal national code of interview (from 1 to 16)</td>
<td></td>
</tr>
<tr>
<td>2. Date of contact</td>
<td></td>
</tr>
<tr>
<td>3. Mode of recruitment</td>
<td></td>
</tr>
<tr>
<td>4. Name of the carer</td>
<td></td>
</tr>
<tr>
<td>5. Age of the carer (18+)</td>
<td></td>
</tr>
<tr>
<td>6. Gender of carer</td>
<td>Female ①  Male ②</td>
</tr>
<tr>
<td>7. Do you care for your spouse/partner, your parent, your parent in-law aged 65 or more?</td>
<td>Spouse/partner ①  Parent ②  Parent in law ③</td>
</tr>
<tr>
<td><em>(If none apply, stop the selection)</em></td>
<td></td>
</tr>
<tr>
<td>8. Name of the cared for person</td>
<td></td>
</tr>
<tr>
<td>9. Age of the cared for person (65+)</td>
<td></td>
</tr>
<tr>
<td>10. Gender of the cared for person</td>
<td>Female ①  Male ②</td>
</tr>
<tr>
<td>11. Does your relative require substantial help on a daily basis with intimate hygiene such as cleaning, changing pads, toileting, due to urinary and/or faecal incontinence?</td>
<td>Yes ①  No ②  <em>(stop the selection)</em></td>
</tr>
<tr>
<td>12. Are you the family member who regularly helps your relative with this type of care?</td>
<td>Yes ①  No ②  <em>(ask to be put in contact with the family member who helps, if any)</em></td>
</tr>
<tr>
<td>13. Does your relative need some help with walking or for getting around indoors, or uses assistive devices for walking such as a walking stick, walking frame?</td>
<td>Yes ①  No ②</td>
</tr>
<tr>
<td>14. Has the doctor given any diagnosis for (or prescribed any medicine for) memory problems (such as dementia), affecting your relative, if any?</td>
<td>Yes ①  No ②  <em>(if both ‘in-grey’ responses are answered, stop the selection)</em></td>
</tr>
<tr>
<td>15. Telephone number/e-mail</td>
<td></td>
</tr>
<tr>
<td>16. Date and time for the interview</td>
<td></td>
</tr>
<tr>
<td>17. Location for the interview (including address, if relevant)</td>
<td></td>
</tr>
</tbody>
</table>
The Interview: Topic Guide

- Re-iterate purpose of project and its main topic (that is experiences of the main carer in taking care of urinary and faecal leakages of the older person), as described during the first contact (at page 1) and reported in the Research Protocol.
- Request permission to use a tape recorder and ask them to sign two consent forms; one for them to keep and one for the research team.
- Icebreaking: warm up the interview with light conversation before starting (the journey to the location of the interview, the local area, etc). This will be context-specific.
1. **Care History:**

Can you tell me a little bit about how you came to start helping to care for your relative?

**18. What factors influenced your decision to provide care?**

<table>
<thead>
<tr>
<th>Factor</th>
<th>daily</th>
<th>3-4 times a week</th>
<th>1-2 times a week</th>
<th>More rarely</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>Economic reasons (cost of professional care is too high or similar) vs emotional bonds (love, affection)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**19. How long have you been helping your relative with his/her incontinence care?**

**2. Daily routine regarding incontinence care:**

Can you describe for me a typical day for you as a carer? Please tell me what you do from when you get up to when you go to bed, and especially with regards to helping your relative with incontinence care? (show the 24-hours leaflet where appropriate/if necessary)

Can you describe for me a typical situation in your daily life when your relative experiences urinary and/or faecal leakages? Can you share with me a specific example or story that helps to highlight this experience for you and your relative?

What problems do you usually experience when you give this type of care?

How do you try to overcome them?/What strategies do you have?

**20. What kinds of help and support do you usually carry out and how often?**

<table>
<thead>
<tr>
<th>Task</th>
<th>(tick all that apply)</th>
<th>daily</th>
<th>3-4 times a week</th>
<th>1-2 times a week</th>
<th>More rarely</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Intimate hygiene such as cleaning, changing pads, toileting, due to urinary and/or faecal incontinence</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
21. Can you give me more details about your relative's incontinence? For example, what kind of incontinence your relative has (urinary/faecal?), how often it occurs?, when does it usually occur (daytime/night-time?).

22. What absorbing products/aids/devices do you normally use for managing your relative's urinary/faecal leakages and for providing care with intimate hygiene? Show the leaflet ‘products for incontinence’

23. Whereabouts do you normally help your relative with changing their incontinence products and what do you actually do to help? (standing beside the toilet, laying on a normal bed, laying on a bed adapted for disabilities, with the possibility to adjust the height, etc.)

24. In what ways, if any, does the help you give your relative with incontinence care differ from other caring tasks that you carry out? Why is it different, do you think, from other caring activities you carry out? What makes it special if anything?

3. Impact, feelings and experiences of caregiving:

Can you describe the impact of caregiving for an incontinent relative on your social life?

How does it affect your overall wellbeing?

How do you feel when you care for your loved one and in particular when you help them with urinary/faecal leakages?

Do you think that your relationship with your relative has changed or been affected in any way because you help them with their incontinence care? If so, how?

Has your relationship with other family members been affected because of your caring activities relating to your relative's incontinence needs? If so, how?

What are the most challenging or difficult aspects of caregiving for you?

Looking at the other side of the coin now, what are the most positive or satisfying aspects of caregiving for you that help you to continue caring for your relative?

25. Has caregiving caused any change in your/your relative's living arrangements, for example requiring you to move in and live in the same household as your relative? Ask if living together

26. Has caregiving caused any restrictions in your working life and career? (if appropriate and depending on the age of the carer)

27. Have you ever considered giving up caring because of the impact incontinence care activities have on your own life or well-being?

Have you ever considered giving up work because of the impact incontinence care activities have on your own life or well-being? (if working)

28. Do you ever feel that you and your relative are confined or trapped at home because of your relative's incontinence needs?
<table>
<thead>
<tr>
<th>COPE INDEX ADAPTED TO INCONTINENCE CARE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Please answer to the following questions by indicating the frequency that best suits to you.</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>COPE1</td>
</tr>
<tr>
<td>COPE2</td>
</tr>
<tr>
<td>COPE3</td>
</tr>
<tr>
<td>COPE4</td>
</tr>
<tr>
<td>COPE5</td>
</tr>
<tr>
<td>COPE6</td>
</tr>
<tr>
<td>COPE7</td>
</tr>
<tr>
<td>COPE8</td>
</tr>
<tr>
<td>COPE9</td>
</tr>
<tr>
<td>COPE10</td>
</tr>
<tr>
<td>COPE11</td>
</tr>
<tr>
<td>COPE12</td>
</tr>
<tr>
<td>COPE13</td>
</tr>
<tr>
<td>COPE14</td>
</tr>
<tr>
<td>COPE15</td>
</tr>
</tbody>
</table>
4. Resources and social support:

Do you currently have any outside help in caring for your relative, in particular with regards to incontinence care?

29. Which care professionals are currently supporting you, in particular with regards to incontinence care?

<table>
<thead>
<tr>
<th>(tick all that apply)</th>
<th>yes</th>
<th>no</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. General practitioner</td>
<td>①</td>
<td>①</td>
</tr>
<tr>
<td>2. Medical specialist (urologist, etc.)</td>
<td>①</td>
<td>①</td>
</tr>
<tr>
<td>3. Nurse</td>
<td>①</td>
<td>①</td>
</tr>
<tr>
<td>4. Helper or care assistant for older person’s personal/incontinence care</td>
<td>①</td>
<td>①</td>
</tr>
<tr>
<td>5. Occupational therapist</td>
<td>①</td>
<td>①</td>
</tr>
<tr>
<td>6. Social worker</td>
<td>①</td>
<td>①</td>
</tr>
<tr>
<td>7. Counsellor</td>
<td>①</td>
<td>①</td>
</tr>
<tr>
<td>8. Voluntary worker</td>
<td>①</td>
<td>①</td>
</tr>
<tr>
<td>9. Paid (private) care workers/ personnel including migrant workers</td>
<td>①</td>
<td>①</td>
</tr>
<tr>
<td>10. Others specify________________________</td>
<td>①</td>
<td>①</td>
</tr>
<tr>
<td>11. Others specify________________________</td>
<td>①</td>
<td>①</td>
</tr>
<tr>
<td>12. Others specify________________________</td>
<td>①</td>
<td>①</td>
</tr>
</tbody>
</table>

30. Do your family and/or friends regularly provide you with help and support so that you have some time for yourself? What aspects of caregiving do they help with and how often?

<table>
<thead>
<tr>
<th>What tasks do other persons from your network of friends and family provide help and support with and how often?</th>
<th>daily</th>
<th>3-4 times a week</th>
<th>1-2 times a week</th>
<th>More rarely</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>(tick all that apply)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Intimate hygiene such as cleaning, changing pads, toileting, due to urinary and/or fecal incontinence</td>
<td>①</td>
<td>②</td>
<td>③</td>
<td>④</td>
<td>⑤</td>
</tr>
<tr>
<td>2. Physical/personal (e.g. dressing, eating, grooming, etc.)</td>
<td>①</td>
<td>②</td>
<td>③</td>
<td>④</td>
<td>⑤</td>
</tr>
<tr>
<td>3. Domestic (e.g. housework )</td>
<td>①</td>
<td>②</td>
<td>③</td>
<td>④</td>
<td>⑤</td>
</tr>
<tr>
<td>4. Emotional /Psychological /Social (e.g. companionship, reassurance)</td>
<td>①</td>
<td>②</td>
<td>③</td>
<td>④</td>
<td>⑤</td>
</tr>
<tr>
<td>5. Mobility in the home environment</td>
<td>①</td>
<td>②</td>
<td>③</td>
<td>④</td>
<td>⑤</td>
</tr>
<tr>
<td>6. Transports outside home</td>
<td>①</td>
<td>②</td>
<td>③</td>
<td>④</td>
<td>⑤</td>
</tr>
<tr>
<td>7. Organising and managing care and support (e.g. contacting services)</td>
<td>①</td>
<td>②</td>
<td>③</td>
<td>④</td>
<td>⑤</td>
</tr>
</tbody>
</table>
What tasks do other persons from your network of friends and family provide help and support with and how often?

<table>
<thead>
<tr>
<th>Task</th>
<th>Daily</th>
<th>3-4 times a week</th>
<th>1-2 times a week</th>
<th>More rarely</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>8. Taking care for dozing and using drugs</td>
<td>☐</td>
<td>☐</td>
<td>☑</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>9. Others specify_________________________________________________</td>
<td>☐</td>
<td>☐</td>
<td>☑</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>10. Others specify_______________________________________________</td>
<td>☐</td>
<td>☐</td>
<td>☑</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

31. What changes in the home environment are necessary to make it easier for you to manage your relative's intimate hygiene needs?

6. Wrapping up:

32. What would make your day to day life easier as a carer? Allow the person talk and then check the 5 most important solutions among those listed in the table below.

33. In your experiences as a carer who or what do you consider to have been the greatest help for you in coping with your relative's incontinence care?

34. What would your advice be to a novice carer who has just started to help their relative with intimate hygiene tasks?

35. Are you happy/satisfied with the incontinence care you're providing for your relative?

Link to q. 32 (tick the five most important ones to you) yes no

1. Advice from care professionals (GP, nurse, etc.) to learn more about urinary/faecal leakages and possible treatments (drugs, pelvic floor exercises) ☐ ☐
2. Accessible information about the types of help and support that is available for persons with incontinence and their carers and how to obtain it ☐ ☐
3. Consumer guides for selecting the appropriate products/devices for dealing with incontinence and facilitating intimate hygiene needs of relatives ☐ ☐
4. More effective products for dealing with leakages ☐ ☐
5. Training and education to help me develop the skills I need to take care of the incontinence needs of my relative ☐ ☐
6. Opportunities to attend a carer support group to share my problems with others ☐ ☐
7. Possibility to obtain moving and handling aids / supporting devices / adaptations to the home environment at subsidized prices ☐ ☐
8. Respite care (possibility for the carer to have a short break from caring, either in-home respite, such as a sitting service for the cared for person, or care provided outside the home for the cared for person, such as regular attendance at a day centre or a regular short stay in a long-term care setting for the cared for person to give the carer a regular break from caring.) ☐ ☐
9. More practical regular help from care services ☐ ☐
10. Sharing caring activities with other family members ☐ ☐
11. Help with planning for the future care ☐ ☐
12. More money to help provide good care/integrating the help available ☐ ☐
13. Others specify_________________________________________________ ☐ ☐
14. Others specify_________________________________________________ ☐ ☐

DEMOGRAPHIC AND HEALTH STATUS SECTION

And finally we would like to ask you a few background questions about you and some
questions about your relative’s health and related care needs.

<table>
<thead>
<tr>
<th>36. What is your marital status? (tick one answer)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Married or living together                       ①</td>
</tr>
<tr>
<td>In an intimate relationship but not co-habiting   ②</td>
</tr>
<tr>
<td>Single never married                            ③</td>
</tr>
<tr>
<td>Separated/divorced                               ④</td>
</tr>
<tr>
<td>Widowed                                         ⑤</td>
</tr>
<tr>
<td>No answer                                       ⑨</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>37. Which of the following best describes your current employment status? (tick one answer)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employed full time                             ①</td>
</tr>
<tr>
<td>Employed part-time                             ②</td>
</tr>
<tr>
<td>Self-employed                                  ③</td>
</tr>
<tr>
<td>Housewife/househusband                         ④</td>
</tr>
<tr>
<td>Student                                        ⑤</td>
</tr>
<tr>
<td>Volunteer worker                               ⑥</td>
</tr>
<tr>
<td>Retired                                        ⑦</td>
</tr>
<tr>
<td>Currently unemployed                           ⑧</td>
</tr>
<tr>
<td>Other, please specify__________________________ ⑩</td>
</tr>
<tr>
<td>No answer                                      ⑨</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>38. What is the highest level of education you achieved? (tick one answer)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cannot read nor write                          ①</td>
</tr>
<tr>
<td>Less than primary school                      ②</td>
</tr>
<tr>
<td>Primary school/similar                        ③</td>
</tr>
<tr>
<td>Lower secondary education (without graduation) ④</td>
</tr>
<tr>
<td>Vocational education                          ⑤</td>
</tr>
<tr>
<td>Secondary education/middle school/high school  ⑥</td>
</tr>
<tr>
<td>University/similar                            ⑦</td>
</tr>
<tr>
<td>Other, please specify__________________________ ⑧</td>
</tr>
<tr>
<td>No answer                                      ⑨</td>
</tr>
</tbody>
</table>

In the following questions we will ask you to describe your relative’s cognitive and psychological conditions, behavioral problems and level of dependency regarding activities of daily living.
### Cared for person situation

<table>
<thead>
<tr>
<th>Question</th>
<th>Response</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>39.</strong> How do you rate the memory/cognitive problems of your relative, if any?</td>
<td>0 = ABSENT; 1 = LOW (deficits are not significantly affecting their daily living and require only partial assistance by others); 2 = SEVERE (deficits significantly interfere with their daily living and require complete assistance by others)</td>
</tr>
<tr>
<td><strong>40.</strong> Does your relative act as if he or she is sad or in low spirits? Does he or she often cry? Is he/she particularly anxious?</td>
<td></td>
</tr>
<tr>
<td><strong>41.</strong> Does your relative exhibit any behaviours that are difficult for you to manage?</td>
<td></td>
</tr>
</tbody>
</table>

#### Behavioral problems (tick one response per each row)

<table>
<thead>
<tr>
<th>Behavior</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Wandering in or outside the home environment or behaving in a way that endangers their safety?</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>2. Have difficulty holding normal conversation, have no insight into their problems, or become uncooperative with your requests</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>3. Behave in ways that you find upsetting. For example constantly asking questions, following you around, repeating what has been said, shout and scream for no particular reason or inappropriately dressed or in a state of undress.</td>
<td>1</td>
<td>0</td>
</tr>
</tbody>
</table>

| 42. | How does your relative feel about his/her urinary/fecal leakages? |
| 43. | What is his/her need for help in carrying out activities of daily living? For example, like eating, dressing, personal hygiene (use the Barthel Index in the next page) |
## BARTHEL INDEX

The next questions are about activities that we all need to do as part of our daily lives. If your older relative was alone would they be able to carry out the following activities themselves? If not, do they rely partially or completely on others to perform them?

<table>
<thead>
<tr>
<th>BAR</th>
<th>Activity</th>
<th>Unable</th>
<th>Needs some help</th>
<th>Independent</th>
</tr>
</thead>
<tbody>
<tr>
<td>BAR1</td>
<td>Get around indoors</td>
<td>☐</td>
<td>☐</td>
<td>☒</td>
</tr>
<tr>
<td></td>
<td>Immobile</td>
<td></td>
<td>In a wheelchair without help or walking with major physical help</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Walking with some help guided or supervised</td>
<td></td>
</tr>
<tr>
<td>BAR2</td>
<td>Manage stairs</td>
<td>☐</td>
<td>☐</td>
<td>☒</td>
</tr>
<tr>
<td>BAR3</td>
<td>Move themselves from bed to chair and back, if next to each other</td>
<td>☐</td>
<td>☐</td>
<td>☒</td>
</tr>
<tr>
<td></td>
<td>Unable, no sitting balance</td>
<td></td>
<td>Major help (1 or 2 people, physical)</td>
<td></td>
</tr>
<tr>
<td>BAR4</td>
<td>Use the toilet (or commode)</td>
<td>☐</td>
<td>☐</td>
<td>☒</td>
</tr>
<tr>
<td>BAR5</td>
<td>Use the bath or shower</td>
<td>☐</td>
<td>☐</td>
<td>☒</td>
</tr>
<tr>
<td>BAR6</td>
<td>Keep up their personal appearance (brush hair, shave, make up, etc.)</td>
<td>☐</td>
<td>☐</td>
<td>☒</td>
</tr>
<tr>
<td>BAR7</td>
<td>Dress themselves</td>
<td>☐</td>
<td>☐</td>
<td>☒</td>
</tr>
<tr>
<td>BAR8</td>
<td>Feed themselves</td>
<td>☐</td>
<td>☐</td>
<td>☒</td>
</tr>
<tr>
<td></td>
<td>Yes, frequent accidents</td>
<td></td>
<td>Yes, occasional accident</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Once a day or more</td>
<td></td>
<td>Less than once a day</td>
<td></td>
</tr>
<tr>
<td>BAR9</td>
<td>Does Elder have accidents with their bladder (incontinence of urine)?</td>
<td>☐</td>
<td>☐</td>
<td>☒</td>
</tr>
<tr>
<td>BAR10</td>
<td>Does Elder have accidents with their bowels (incontinence of faeces)?</td>
<td>☐</td>
<td>☐</td>
<td>☒</td>
</tr>
<tr>
<td></td>
<td>Once a week or more</td>
<td></td>
<td>Less than once a week</td>
<td></td>
</tr>
</tbody>
</table>

Total (0-100)