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CHALLENGES FOR MEN, PROVIDING INFORMAL CARE FOR PEOPLE WITH DEMENTIA

Abstract. The article highlights the care provided by men for their partners or parents with dementia and the main challenges they face in the process. Using Van Gennep’s rites of passage model, which distinguishes three stages of the individual’s transition to a new social role (separation, liminality, reconnection), the author analyses six interviews with informal carers that shed light on their experiences and changes, while looking for those experiences brought by care responsibilities into the informal carers’ everyday lives and how they adapt to the needs of people with dementia. In analysing how men cope with feminised care practices, the findings show the potential to alter both the traditional ascription of care to women and certain needs of caring men like gender-specific support from public services, better communication with healthcare professionals and emotional support.

Keywords: informal care, men, dementia, van Gennep’s rites of passage model

Introduction

Dementia is a progressive and incurable brain disease (Graham and Warner, 2014). People with dementia need wide-ranging care and, because they typically live at home, informal carers provide most of the care required. Care for people with dementia entails a complex, demanding and changing phenomenon. The organisation of care at the individual level is understood in this article as not only the practical exercise of care activities, but as a process that changes over time and involves mutual relationships in care networks (Kruijswijk et al., 2015; Filipović Hrast et al., 2005). The article focuses on male informal care providers and their experiences of caring for partners and parents with dementia.

Informal care in the family remains largely gendered, class-marked and often an involuntary choice (Umberson et al., 2014; Hrženjak, 2010; Lutz,
Even though the situation is changing and men are becoming more engaged, the Eurofamcare\(^1\) survey reveals that, for instance, informal elderly care providers are mostly women (76%), 60% are children (including daughters- and sons-in-law), and the average duration of care is 60 months (Hrženjak, 2018: 78). Nevertheless, Collins (2014) shows that approximately one in every three elderly care providers is a man, of whom 30% are sons. Specific life situations or circumstances led to their engagement in informal care, what involves their negotiations of traditional masculinity norms.

Available data for elderly care in Slovenia show that around two-thirds of informal carers in the family are women (Hvalič Touzery, 2009). A recent representative research study\(^2\) (Šadl and Hlebec, 2018) reveals that sons only take care of their parents in specific circumstances, like living in a common household, being a single child, or due to economic scarcity. Sons therefore mainly take over care responsibilities when there is no other choice. Gender differences are evident in the intensity and scope of care activities which are larger in scope and intensity when provided by daughters than sons (Šadl, 2018).

Knowing that gender inequality exists in informal care, it is particularly interesting to learn more about men’s experiences regarding when they cannot or do not want to delegate/outsource care responsibilities to other family members or institutions. Recognising their experiences may contribute to better understanding of how care is socially constructed and gendered. Therefore, the main purpose of the article is to explore the experiences and narratives of men who take care of their partner or parents with dementia in order to understand how masculinity is negotiated by doing/undoing gender in informal care. The next research question concerns the specific experiences of men who take care of their partner/parents with dementia within the three stages of Van Gennep’s ritual of passage. The article begins with a conceptual framework, presents the methodology and sample used and then outlines the interview analysis. The analysis of three stages of passage in the informal care processes and challenges in male informal carers’ everyday lives constitutes the article’s core focus.

**)(Un)doing gender within informal care processes**

The core conceptual framework underpinning the article includes concepts of (un)doing gender (West and Zimmerman, 1987; Deutsch, 2007), masculinity and care (Hanlon, 2012), and van Gennep’s threefold model of

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\(^2\) Data were collected in 2013; 1,151 informal caregivers completed the survey, of whom 779 were family caregivers who provide care for a partner, mother or father and mother-in-law or father-in-law (Šadl and Hlebec, 2018: 740).
rites of passage (Van Gennep, 2000). West and Zimmerman (1987) developed the concept of “doing gender”, which implies that differences between women and men that are not natural, essential or biological, but are (re)produced in everyday interactions, actions and behaviours. A concept of doing gender assumes a complex of socially guided perceptual, interactional, and micropolitical activities that cast particular pursuits as expressions of masculine and feminine “natures” (West and Zimmerman, 1987: 126). “Doing gender” is considered a central concept in gender research where the focus is on how people observe and make gender relevant in their everyday behaviour and practices. Gender is not simply understood as a tool for understanding the relations between women and men or explaining the identities. It also enables understanding of the relationships and processes that systematically produce these groups and identities, and understanding of the gendered character of institutions, norms and practices within which the gendered power relations are reproduced (Hrženjak and Jalušič, 2011).

Gender is perceived as behaviour by which individuals are constituted as men or women in the eyes of others (Šadl, 2018). Women act like women because the positions they occupy require feminine behaviour. Men act like men because the social positions they occupy require competence, leadership, physical strength and autonomy (Deutsch, 2007). If the concept of “doing gender” refers to social interactions that reproduce gender difference, Deutsch (2007) suggests using the concept “undoing gender” to refer to social interactions that reduce gender difference.

The image of men in care work does not go along with the usual gender representations since prevailing images of masculinity are equated with power, physical strength, aggression, toughness and resilience, whilst prevailing images of femininity are associated with sexuality, emotion, nurture, sensitivity, compassion and care (Hanlon, 2012: 1). Traditional hegemonic masculinity is different to caring masculinity (Hanlon, 2012). Hanlon (2012) outlines several reasons for the absence of care from traditional constructions of masculinities: because care is defined as feminine, and therefore the position of the carer is seen as a subordinated one; doing care means enacting a feminised identity; care is seen as something men are bad at and care means relinquishing the power associated with traditional masculinity. Therefore, according to Spencer Scott’s (2019) research of gender differences and managing the stress arising in dementia care, men tend to be less socially prepared for taking over care responsibilities and tend to outsource it as they see caregiving as a “job” and a “duty”. They tend to be less likely to ask for help and talk about their feelings. Men describe their relationship with older parents as more “filial” or “egalitarian” and hence will often wait until assistance in daily living is requested by their parents. Men are more often “care managers” of services and provide a good deal of support, but
with the goal of helping their parent(s) to regain independence and self-reliance (Collins, 2014).

Van Gennep’s rites of passage model was used by Barret and colleagues (2014) while analysing the experiences and needs of informal family carers in the areas of childcare, elderly care and care for the disabled. Following Barret and colleagues, the model was applied in Slovenia by Hrženjak (2018: 75–110) in an analysis of informal family carers in elderly care. Taking previous analyses and considerations into account, the model was used in the research presented in that article. By identifying the three stages of an individual’s passage into a new social status and role (separation, liminality, and reconnection), van Gennep’s rites of passage model (2000) allows for the processes of changing, dissolving the previous state, new social roles and related responsibilities, and the need for social integration. The model assumes an individual’s completion of the three stages of the rituals of passage means that the individual has left behind their former social position and been pushed into an intermediate stage that does not resemble the previous or new situation but is ultimately included in the new system of rules, roles and responsibilities. Informal carers experience complex time, spatial and relational changes that are concentrated in the liminal phase, in an uncertain state of intermediation and non-ambiguity (Barrett et al., 2014; Hrženjak, 2018). Broader social support is needed to pass through this phase. Compared with Turner’s “transition ritual” concept (Turner, 2008), which understands the individual’s role as maintaining the balance of society and ensuring community solidarity, van Gennep’s model is more flexible and better adapted to processes that change over a longer time. Turner defined the ritual as part of a social drama process, with the experience of liminality attributed to the group experience (Turner, 2008), while van Gennep’s model precisely exposes the experiences of the individual and the need for wider social support. Van Gennep’s ritual transit model gives analytical insight into which changes are experienced by relatives who in their day-to-day lives take care of people with dementia, and reveals the situations, difficulties and needs they face (Hrženjak, 2018; Barrett et al., 2014).

Methodology

The study is based on six structured in-depth interviews with male care givers in Slovenia. Three respondents were recruited using the snowball sampling method through the researchers’ personal social networks and

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3 The interviews were conducted within the research project Masculinities, Equality, Care Practices (2017–2020), funded by the Slovenian Research Agency and carried out by the Peace Institute in cooperation with the University of Ljubljana - Faculty of Social Sciences. More information about the project: http://www.miroveni-institut.si/en/projects/masculinities-equality-care-practices-mesp/.
the other three through a non-governmental organisation that operates in the field of dementia, Spominčica Alzheimer Slovenia – the Slovenian Association for Dementia Assistance.\textsuperscript{4} The qualitative method proved valuable for researching intimate and sensitive topics. The interviews were audio recorded, transcribed and analysed using a thematic analysis method. In order to ensure the interviewees’ anonymity and protect their privacy, all names were anonymised. It turned out that anonymisation was especially relevant in smaller towns where the men perceived their situation to be specific and holding great potential for disclosure.\textsuperscript{5}

The men in the sample are aged between 47 and 89. They are taking care of a person with dementia in different stages of the disease and with different care needs, and are living in a range of surroundings (from rural areas to large towns) across Slovenia; three men are long-standing primary carers of their partner with dementia, two are taking care of their mother, one of his father. Four interviewees are retired and two are employed. Their net monthly income varies from EUR 643 to EUR 1,200 (EUR 877 on average).

Oto (aged 89) has been taking care of his wife (including intimate care) due to dementia while living at home ever since 2011. She now lives in an elderly home, but he visits her every day. Jure (aged 65) has been taking care of his wife since 2014. Today she lives in an elderly home, but he visits her twice a week; at the beginning, he visited her every day, but now, as he said in the interview, he is exhausted. During the visits, he feeds and communicates with her non-verbally through gestures or touch. Niko’s wife is also living in an elderly home, after he had taken care of her for 15 years. He visits her two or three times a week in order to spend time with her and help her with feeding. They have two children, the daughter is involved in caring to a small extent, while the son has to deal with his own serious illness. Jože (47) lives with his wife and two children but, since he is an only child, all of his family life is subordinated to his parents’ care on an every day basis. Vojak (50) is also an only child, living at home and taking care of his mother since 2003, being the sole care provider after his father suddenly died. Franko (71) changed his place of residence in order to take care of his father with dementia who was forced to move into an elderly home under a court decision. He felt obliged to take care of his father because he is an only child. He visits him twice a week to help him with feeding, carry out intimate care and provide social activities by taking him to places where his father used to go, for example visiting friends and restaurants. Our sample of sons who take care of their parents confirms previous research findings

\textsuperscript{4} An independent, non-profit, interdisciplinary professional association whose primary goal is to provide professional and effective assistance to people with dementia, their relatives and caregivers.

\textsuperscript{5} For a detailed discussion on fear among and the marginalisation of care workers which highlights the need to safeguard their identity, see Bajt et al., 2018.
about elderly care, namely, that men mainly take over primary care when there is no alternative, that is, when they are the only child. Details of the respondent sample are shown in Table 1 (Annex 1).

Table 1: DATA ABOUT THE INTERVIEWEES PARTNERS

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Age</th>
<th>Education</th>
<th>Employment status</th>
<th>Monthly income</th>
<th>Provides care for</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>Oto</td>
<td>89</td>
<td>Secondary vocational education (3 years)</td>
<td>Retired</td>
<td>950 €</td>
<td>Partner</td>
<td>Small town</td>
</tr>
<tr>
<td>Jure</td>
<td>65</td>
<td>Secondary general education (4 years)</td>
<td>Retired</td>
<td>643 €</td>
<td>Partner</td>
<td>Rural</td>
</tr>
<tr>
<td>Niko</td>
<td>66</td>
<td>Secondary vocational education (3 years)</td>
<td>Retired</td>
<td>720 €</td>
<td>Partner</td>
<td>Large town</td>
</tr>
<tr>
<td>Jože</td>
<td>47</td>
<td>Short-cycle higher education</td>
<td>Employed</td>
<td>1,200 €</td>
<td>Mother</td>
<td>Rural</td>
</tr>
<tr>
<td>Vojak</td>
<td>50</td>
<td>Bologna first-cycle professional higher education</td>
<td>Employed</td>
<td>1,100 €</td>
<td>Mother</td>
<td>Rural</td>
</tr>
<tr>
<td>Franko</td>
<td>71</td>
<td>Secondary general education (4 years)</td>
<td>Retired</td>
<td>650 €</td>
<td>Father</td>
<td>Large town</td>
</tr>
</tbody>
</table>

Source: Authors’ own analysis.
* All respondents chose a pseudonym for the provision of anonymity. For the same reason we do not reveal the respondents’ place of residence.

Interviews’ analysis

(Un)doing masculinity in care

The interviewed men reported doing everything themselves and never wanting any help or asking for it, which is consistent with doing masculinity. Oto, for instance, commented that, as long as he is capable of doing it himself, he prefers to do it on his own. Deeper analysis shows they receive some support with the care, for example Oto mentioned a cleaning service and Jože noted occasional help from his family members. There is a gap between how the interviewed men perceive the informal care they provide – they do it entirely themselves – and the reality whereby they actually receive some help. This gap may be explained by the perception that a request for help means recognising one’s own incapacity (Gendron, 2015: 53), holding particular relevance for negotiating masculinity in male carer situations.

Vojak is also negotiating masculinity in a situation where he must provide care for his mother with dementia. While recognising the ‘feminised’ skills the carers of people with dementia must possess, including: empathy,
patience, organisational and communication skills, knowledge in housekeeping, he stated: “I’m basically doing male jobs or those that could be done by anyone”.

On the other hand, most interviewees could not find any reason to explain why they, as men, would provide care work differently to women. Niko (66) commented that he had never thought of such comparisons with women, while Jure responded with self-confidence: “I can’t imagine how this could be done differently”. Oto had some second thoughts about whether a female carer might cook or clean more regularly and precisely. Franko considered that his own care work was at least of the same quality as that of a female, but in some cases he thought that he does it even better because he has a talent for it. Jože reflected on gender stereotypes in care:

_The biggest problem in care is overcoming taboos. I think it’s a lot easier to be thrown into care – you do not need to do it today, but tomorrow you have to do everything. (...) It’s just a stereotype that women have to do this._

Empathy, patience, cleaning, washing, cooking and communication skills are often recognised as feminine and thus Deutsch (2007) believes this might be considered as their “undoing masculinity”/“undoing gender”. Gender is not a static category and research shows that differences between men and women within care work are a result of doing femininity and masculinity according to the prevalent gender norms. The more men understand their role as fixed and follow the dominant gender norms, the less able they are to make the adjustments needed in caring situations.

From the undoing masculinity point of view, Jure and Niko reported not just about their cleaning and cooking, but how they also carry out intimate care for their wives, the same as Franko does for his father. This activity is largely burdened by the stereotypes of being feminised and socially devalued. Also with respect to emotions, the male carers narrated the undoing of masculinity. Franko shared the experience of his father feeling sad and crying in front of him. Jure reported that he cried for 3 days after his wife was placed in institutional care: “I admit it as a man and I am not ashamed to admit that I was crying”. In general, crying is perceived in society as a weakness among males.

The following section presents the men’s experiences when their everyday lives changed after they took over the informal care of their partners/parents with dementia. The analysis focuses on the challenges and needs they encountered in the care process in their everyday lives.
Three Stages in Informal Carers’ Everyday Lives

The fact that informal carers’ experiences are very diverse and dynamic makes van Gennep’s (2000) rites of passage three-stage framework appropriate for an overview of situations of care for people with dementia. In this part, the processes of separation, liminality and reconnection of the male informal carers’ experiences are analysed.

Separation

Van Gennep (2000; Barrett et al., 2014) characterised separation as an event that detaches an individual from their previous social status, and initiates a course of change that redefines their position in their particular social and cultural context. In the informal caregiving context, this means the initial realisation of responsibility for care, the personal decision to assume it, and the act of meeting with formal care services or assessors to develop care plans where the carer is officially recognised as an element of the care arrangements (Barrett et al., 2014). Where care is provided at home, separation creates new spatial, temporal and relational challenges. Jure found himself in the separation phase when everything they had already sorted out collapsed:

We have come to conflicts, usually it happens in this way and this is scientifically proven, when she forgot to pay the bills and similar (...). Now I know that it started then, but it was not clear before.

Jure took over housework and considers he did it well. Oto described doing cooking and cleaning:

From the beginning, I dressed her, I prepared breakfast for her, I gave her breakfast, then we got into the car and drove away. Let’s say, to the shop or wherever was needed and she always went with me. Well, then after a couple of months, she got lost sometimes, if I didn’t pay enough attention.

Vojak encountered the separation phase in a very short period of time: “My father suddenly died and I am the only son. I realised that mum’s health condition is not the best. I was raised this way – it can’t be otherwise”.

Jure experienced the separation phase immediately after his wife was diagnosed with Alzheimer’s dementia. He lacked information on how to handle the care aspect or deal with the disease, bringing anxiety and uncertainty. He described this period as “being lost for 6 months”. After hearing
about the association called Spominčica Alzheimer Slovenia, he attended some lectures and discussions with informal carers. During one lecture, he met a doctor, a specialist in treating people with dementia, and his reaction was quite emotional:

The point is that the doctor called me when she [the wife] was being tested about having dementia or not, and then I just realised what dementia is. I sat behind her, but she wondered what the date was, the season and, when she didn’t know, she was looking for me and then I also got tears in my eyes for the first time when I saw what dementia means.

This is a key problem in the communication between informal care providers and healthcare professionals; namely, it should be ensured that informal care providers are better integrated into the care process. Communication between carers and people with dementia is extremely difficult in itself, especially when the ability to speak declines, and accordingly close cooperation between formal and informal carers should be a compulsory element of complementary and integrated care. Jure confirmed the need to include the informal carer already in the separation phase: “The doctor should ask, the moment they make the diagnosis, who brought you, how did you come, and inform the relatives”. Research shows regular contact between informal care providers and medical staff is very important when organising care for people with dementia (Connel et al., 2001; Cooper et al., 2008). Researchers have investigated the consequences of being confronted with newly emerging dementias, in particular when coupled with anxiety and depression (Cooper et al., 2008). Male informal caregivers face the same problem as women informal caregivers who are affected, distressed and seeking outside help, which might pose a special challenge for them from the traditional masculinity perspective.

Various circumstances can lead to a forced choice to take on care responsibility, in turn requiring that the informal carer adjust their the life to suit the new situation. The level of care needed by a person with dementia always corresponds with the stage of the disease, the living habits of the care receiver, previous relationships between the care provider/receiver, the care network size and the living environment of the care receiver. All of these circumstances strongly influence the second stage in van Gennep’s rites of passage framework.

Liminality

The official diagnosis and taking a decision on who will be the primary carer are followed by a phase of liminality (in-between phase), entailing
adapting to the new situation, namely adjusting the previous life to the new circumstances, as determined by the care receiver’s needs. An informal carer is pushed into an intermediate state whose characteristics are unlike the previous or new positions. According to Barret and colleagues (2014), family carers are in a liminal position when they are neither professional care providers, nor passive family members. In this phase, primary care providers take on greater responsibility, including communication with their relatives to accept decisions on future steps regarding the person with dementia. Due to their new circumstances and roles, care providers also often face spatial, temporal and relational dimensions within the liminality phase.

In this phase, the care needs of the person with dementia are growing and a need arise to take over intimate care, which may prove especially difficult for men by challenging their masculinity. Although the three interviewees suggested their spouses were given intimate care and reported no major problems, they said that during this stage they began to intensively consider institutional placement. In this stage, they were confronted with feelings of guilt and sadness. Oto’s experiences show how providing adequate care for someone with dementia is a changing process associated with challenging decisions and the distress the care provider is facing:

It was getting worse, but I was pleased with this since she went everywhere with me and it was fine. But once she could no longer be alone in the toilet, then it was harder. Then it was very difficult, and I had to wash her... (...) That was 2 years ago. (...) Then I could not stand it anymore, and I said that, now, something will have to be done differently.

The liminality stage in our research is also illustrated by Vojak. A typical male ‘care manager’ of services, he provides considerable support to his mother who is still capable of being alone for some time and does not need her son’s constant presence or care. He described the variety of care needed on a weekly basis, including the unpredictability that accompanies the everyday life of an informal carer:

I am taking care of my mum, this year, she is turning 80. As far as healthcare is concerned, this means transport to a doctor, to a pharmacy, a hospital, emergencies, arranging referrals – now the references are all electronic. Then ordering doctors, specialists, this is the primary part. Transportation, socialising, then I take care of the house, the surroundings, care of the medicines, but I do not provide her with intimate care. The weekly timetable varies according to her state of health – from 20 to 100 hours.
Franko’s father was placed in a home for the elderly and this led to Franko making spatial, temporal and relational adaptations to his everyday life to better care for his father. To be able to regularly visit his father, he moved from Ljubljana to a small town close to the elderly home. The temporal change requires Franko to adjust his daily or weekly activities to ensure regular visits to his father.

_I visit him practically every other day and then twice, three times, a week we go out of the home for a couple of hours, sometimes a whole day. He still feels that he is imprisoned, that his freedom is limited, because for his entire life he was very independent._

The relational change for Franko is two-fold: in relation to his partner who still lives in Ljubljana, and in relation to his father who did not take care of him while Franko was a child. Franko’s partner is very emphatic regarding his father’s care since she herself is a carer for her mother who also lives in Ljubljana. They both have to consciously and constantly nurture their partnership. Such partnership demands greater planning, but since they are both involved in caring for their parents, they understand and support each other. There had also been a change in Franko’s relationship with his father since they were not close when Franko was young. Franko shows his respect for him when saying: “I feel that in the last couple of hours a father has, that I would somehow, despite the dementia, try to give him a few bright moments”. Franko as a son wants to be a better carer than his own father was for him as a son.

In the liminal phase, it is vital that informal carers are given support services that respond to their needs. Informal care providers in this phase must receive the support required to handle the complexity of care and to not forget about their own lives. Many researchers (Manthorpe et al., 2018; Cooper et al., 2008; Connell et al., 2001) note the difficult situation family carers are in, taking care of someone with dementia. In the long run, stress, anxiety and physical or mental exhaustion are the daily reality of care providers. The complexity of the tasks involved sometimes leads them to burn out. In our research sample, the male carers take time for themselves in order to relax or at least de-stress. Jure reported on having joined the bowling club, Oto on going for regular walks, Jože on cycling, others on fishing, hiking and gardening. This is an important difference between the male and female informal carers, with women more often totally subordinating themselves to care and being more likely to burn out (Hrženjak, 2018). It seems that men carers, at least those in our sample, also pay close attention to self-care, which is an interesting finding.
Reconnection

Van Gennep’s model defines reconnection as a shift towards a new, socially recognised and valued life stage with its own set of rules, roles and obligations (Barrett et al., 2014). Reconnection is only possible through the social recognition and support of the informal carer, when public services and social networks adequately respond to their needs and new social role (Barrett et al., 2014). Many informal carers experience ongoing liminality, without reaching reconnection. In our research, after years of liminality Oto, Jure, Niko and Franko reached the reconnection stage when their spouses were placed in an elderly home. This means they were no longer the primary carers in an everyday routine of intensive and intimate care, but their partner’s care was being shared with the public care system. They had re-arranged their lives in this stage such that they now regularly visit their partners in the elderly homes, yet they still reported how much they miss them, struggle with loneliness and empty days. Oto admitted: “I miss her so much”. Jure also said: “I’m lost, still”. Niko reflected on his new situation: “Now I keep telling myself, I have to enjoy myself, but I can’t. It’s slowly getting a little better now, but it’s been such a shock”. The men in our sample experienced their caring situation as transformative, with their caring experience revealing their sensibility, vulnerability and deep emotional connections with their partners/parents.

This phase in the care process requires for social recognition and an adequate response by public services. Therefore, policy recommendations offered by informal carers themselves, based on their own experiences, are very relevant for ensuring informed care policies. Our interview partners and their first-hand experience suggested several supporting mechanisms for informal carers: information and support from the local environment, including information brochures with guidelines for informal carers when a diagnosis is made; comprehensive treatment of people with dementia; close cooperation among formal and informal caregivers; public and universally-accessible support services; respite care; a telephone helpline; organisation of transport or mobile shops and mobile pharmacies (especially in more remote villages), etc.

Our interviews with the male informal carers also reveal positive aspects of caregiving that are often overlooked when seeking to understand the experiences of informal carers. Jože reported on a better relationship with his mother with dementia, but also with other relatives, his wife and his children. Franko described his feeling of self-esteem from being a good man while taking care of his father with dementia. The informal male carers of people with dementia displayed a sense of personal accomplishment and gratification, feelings of mutuality in a dyadic relationship, an increase in
family cohesion and functionality, and a sense of personal growth and purpose in life, as also found in international research (Yu et al., 2018; Lloyd et al., 2014).

**Conclusion**

This article highlights the role played by men in informal care for their partners and parents with dementia for the purpose of better understanding how masculinity is negotiated by doing/undoing gender. The in-depth analysis pointed to the changes and challenges male informal caregivers’ face in their everyday life and social roles because of their care responsibilities and how they have to adapt to their care receivers’ needs. Since one-third of all informal carers are men, it is important to make their experiences visible because they prove that men can provide care too and that gendered care work is socially constructed. Men carers consider the care they give is of the same quality as the care provided by women; they demonstrate that care work is demanding, but that somebody has to do it.

The men’s specific experiences while taking care of their partner/parents with dementia within the three stages of van Gennep’s ritual of passage were emphasised. The analysis underscores the challenges of not recognising the disease, the shock of the diagnosis and the insufficient information available for male care givers in the separation stage. Further, it includes the initial realisation that someone needs to take responsibility for care, the personal decision to take it on, and the key problems in the communication between informal care providers and healthcare professionals, given that informal care providers should today be better integrated into the care process. The further processes of liminality and reconnection are closely connected to the development of the disease. Many informal carers experience ongoing liminality. Within this phase, primary care providers must adapt their previous life to suit the new circumstances and assume greater responsibility. Various challenges were revealed. Franko’s case showed he made spatial, temporal and two-fold relational adaptations to his everyday life to meet the caring needs of his father. Vojak, as a typical male ‘care manager’, encountered the challenge of adapting to the unpredictability of his mother’s care needs. Jure, Niko and Franko reported on cleaning, cooking, providing intimate care but, above all, the emotional difficulty of the caring situation that confronted their traditional way of doing masculinity. One of the specifics of men in informal care is that, at least partners who care for their spouses with dementia, rely on little outside help from family members and public institutions, which is consistent with doing masculinity. Still, there is a gap between how they perceive the informal care they give to their parents or partners and the reality whereby they actually receive some help and yet
they still perceive it as something they do all by themselves. Through the gender differences perspective, male carers pay greater attention to their self-care than female carers do. The reconnection phase requires social recognition, an adequate response of public services and providing supporting mechanisms for informal carers. They have re-arranged their lives and combine informal care with formal care, that is, visiting their parents/partners in the elderly homes. Close cooperation among various stakeholders in the care process is therefore extremely important for informal carers as well as their partners and parents with dementia.

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