

Henrik Eriksson, Jonas Sandberg and Keith Pringle
'It feels like a defoliation...': Older men's notions of informal support as primary caregivers

Abstract

Little interest has been given to painting a broader picture of men's relation to caring and care giving activities and when it has, it has often tended to uphold stereotypic notions regarding men's attitudes to caring activities. This article explores older men's account of becoming and being primary caregivers as a result of unexpected life events. By interviewing eleven older men in three focus group sessions questions about masculinity and the cultural understanding about being older men in relation to caregiving and support was approached. In our result we describe the caregiving men's social and personal changes as a consequences of caregiving as a defoliation process where the difficulty in upholding relationships with unconventional men and the caregiving men's difficulty in upholding relations with people, who embrace hegemonic ideals about masculinity, is framing their lives as caregiving men.

From this position caregiving men reach out and connect with other men who share the same experiences. We suggest that in the network of men who are, and is about to become, primary caregivers, the principle of "paying it forward" seems to be understood as the most valued support. Paying it forward help the men to uphold their caring experience as valuable and gives the men a position as skilled.

Key Words

Older men, caregiving, support, reciprocity, relationships, understanding

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Men and Caregiving – a critical review

“I walk a lonely road. The only one that I have ever known. Don't know where it goes. But it's home to me and I walk alone”. The lyrics of the punk-rock band Green Day can highlight some significant questions about men's culture in the western society in a wider sense and more specifically on older men's views on themselves as carers. As Russel (2007) pin points, elderly men who become carers to their partner in late life enter a world that predominantly has strong conceptual connections with social arrangements relating to their female family members such as wives, daughters, daughters in law etc. However, with few exceptions, little consideration has been paid to the importance of the social experiences of older caregiving men and there is a need for further understanding of how older men experience the onset and progression of caregiving. The Swedish project 'MeCaLL – Men as caregivers in late life' has been initiated in order to examine and improve older men's opportunities and in turn increase their ability to develop their role as informal caregivers.

As Connell (2005) has recently re-iterated, we desperately need local/regional studies relating to men's practices to help us to build up a mosaic of global understanding. Furthermore, the Nordic states – and especially Sweden – occupy a unique position in transnational analyses of welfare systems generally and of gender regimes in particular since they are often assumed to represent a progressive “acme” in terms of the global picture concerning both fields. As such, an analysis of these states has a particular salience.

In studies of men and masculinities little interest has been given to painting a broader picture of men's relation to caring and caregiving activities. For example in the recent internationally published encyclopaedia (Flood *et al* 2007) of men and masculinities the term 'caring' is not listed whilst the term 'violence' is given seven pages loaded with references to international research. Also, researchers who elaborate on men and caring argue that men and caring activities are not so compatible (cf. MacDougall 1997, Williams 1997, Evans 2002). Some of the most recent Swedish research on men and caring, such as Havung (2000), Dahle and Widding Isaksen (2002) and Robertsson (2004), also tend to uphold the above notions regarding men's attitudes to caring activities. These recurrent

results also contribute to upholding the idea that caring can be regarded as an exclusively woman's responsibility.

There is a lack of literature about men and caring and, more specifically, a lack of literature on male caregivers that, from the perspective of the latter, might challenge gender as a dichotomous variable. However, there is research from other domains which suggests that older men are engaged in caregiving activities to the same extent of time as older women. Kristensson-Ekwall *et al* (2004) even argues that in some contexts older men might provide more informal care than older women do. This challenges earlier assumptions that men to a large extent do not get involved in caring activities and raises new questions. What men's experiences of caring mean and entail, not only for potentially subversive constructions of masculinity, but also what they mean for normative constructions of masculinity is yet to be further researched. Studies about older men as caregivers, addressing aspects about caring and identity, can therefore make important contributions to the critical understanding about men and masculinities.

Men and Intimacy –a subversive challenge

Earlier studies in the MeCaLL-project (Sandberg and Eriksson 2007, Eriksson and Sandberg 2007) have suggested that older caregiving men experience a close and intimate relation with their partner that is not un-problematic when having to deal with intimate caring activities. The body care aspects are regarded as being both time-consuming and mentally difficult for the men but the engagement in caregiving also gives the men a feeling of closeness, fulfilment and meaning in life. It is interesting to note that this occurs at a time in life when many men experience a lack of fulfilment due to retirement and experiences of bodily dysfunction (Hearn 1995, Pringle 1995, Sabo and Gordon 1995).

When older men become primary caregivers for an ill partner they experience social and personal changes in their existence, but might lack knowledge about how to cope with the changes and experiences. Due to minimal caregiving earlier in life older men are often largely unaware about in how to undertake and perform caregiving activities (Eriksson and Sandberg 2007). In the physical caring, it is impossible to avoid intimacy. On the contrary, intimacy is constantly present when caring for a vulnerable person. One has to handle perspiration, vomiting, blood, urine and defecation. We argue that this form of non-sexual intimacy with another person and their body fluids is inconsistent with the many dominant discourses about masculinity in Sweden. The predominant discourses about gender equality in Sweden tend to make gender visible and at the same time, in many situations, downplay its importance. As such they are a constant reminder of hegemonic masculinity construction. This arises from the fact that one important discourse focuses on gender equality as being based on sameness between women and men; whilst another gender equality discourse – equally important – focuses on gender differ-

ences (Magnusson 2002). One consequence of this is that physical and symbolic ideas about gender differences can be strengthened even when the societal aim is to foster present and future citizens to disregard or transcend these categorisations that have their origin in dichotomised ideas about two distinct genders. Though it is claimed that gender differences tend to diminish in later life (cf Gilligan 1982), it is important to address the fact that men who enter caregiving and undertake caring tasks also enter a process where the question of normality has to be re-defined. The caregiving process involves a reevaluation of life values, of self as well as a reconstruction of identity.

Therefore, it is important to address the fact that older men, through various strategies, seek to maintain continuity in their relationship with their partner as well as to create new roles in order to cope with life changes (Sandberg 2001, Sandberg and Eriksson 2007). To be accountable for a caring relationship includes opportunities for experiencing subversive ways of being a man. However, the men’s lack of knowledge in how to cope with such changes in life raises questions about how to support men as primary caregivers.

Older men’s need for support during caregiving is something that has been pointed out in earlier studies (Harris 1993, Ducharme 1995, Schmall 1995, Kaye 2002, Ducharme *et al* 2006) but there are only a small number of studies that have undertaken a critical analysis of masculinity and caring in relation to support. Kirsi, Hervonen and Jylhä (2000) imply that there is a tension between being a caregiver and being a man that has to be recognized when the meaning of support is discussed and elaborated upon. Male caregivers tend to approach caregiving “with a rather stoic, stiff upper lip orientation” (Kaye 2002, 363) and Kaye and Applegate (1990) argue that men internalize social attitudes that prevent them from “going public” with their situation. As Coe and Neufeld (1999) have shown, male caregivers are reluctant to use formal support and when they do a crisis has already occurred or the caregiving responsibilities have become too intense. This pattern is strikingly similar to the findings in other studies (Hearn and Kolga 2006, Hearn and Pringle 2006) regarding men’s reluctance to seek medical help for themselves. The cultural understandings about being a man are therefore something that is important to understand when you address the question about support in relation to older men as caregivers (Eriksson and Sandberg 2007, Ducharme *et al* 2006).

Caregiving men and support

In order to comment on and elaborate previous research, a focused analysis was made of older men’s account of becoming and being primary caregivers as a result of unexpected life events. This study was undertaken as a way of not only providing insight and adding knowledge regarding the cultural understanding about being older men in relation to caregiving and support, but also exploring questions about masculinity.

A purposeful sample of eleven older men was recruited through the local relative centre in a mid size town in the Stockholm region. The participants were all native Swedish citizens, retired from work and between 67 and 80 years old. They were all married with women and had cared for their partners, suffering from dementia, between two and fifteen years. It is important to emphasise that caring for a relative suffering from dementia is likely to differ from caring for a relative with, for example, a stroke because the dynamic inter-relationship gradually diminishes over time (Brereton and Nolan 2000, Keady 1999, Keady and Nolan 2003). Three focus groups were formed containing 3–4 persons and focus-group interviews (Mertens 1998) were conducted in the facilities of the local relative centre. Focus groups centre on interaction among participants as a way of accessing data that emerges when encouraging participants to exchange anecdotes, share and comment on each other's experiences on a collective activity (Kitzinger and Barbour 1999). In this study, the collective activity was the shared experience of being a caregiver for a partner suffering from dementia. From the in-group sharing can emerge considerable insight about men's caregiving experiences. However, the process also has some limitations that are important to consider. For example, participants may feel constrained in contributing fully or openly in front of others. Also, there is a possibility that the group is more in focus than the individual.

However, as the men during the interviews took us through the phases of caregiving and their notions of support, via their experiences, they shared their life stories not only with us as researchers but also with each other. Throughout the interviews, which lasted about two hours, the men listened carefully to each other and acknowledged the stories that are told. Throughout the interviews, they also provided each other with suggestions about where to turn to for help.

When analyzing the interviews a constructivist perspective was used. This perspective stresses that people are not observing an objective reality nor are they taking in information that is just there. Instead people are constructing and reconstructing their own interpretation of reality (Kvale 1996, Rodwell 1998). The departure point in this study is therefore that gender is something that is unstable and thus something that interacts within people's lives and also within the process of collecting and interpreting data. Since rich and full descriptions of the participants' daily lives and notions of informal support were desired, the transcribed protocols were analysed using three steps. The first step was to approach and analyse the entire text. The second step was to reduce the transcribed interviews in relation to the aim of the study. The transcribed interviews were analysed in their original language and translated into English and checked for accuracy by the authors when writing up the paper. The final step of the analysis was to examine the patterns referring back to a new re-presentation.

We recognize that the interviews, like any other interactions, take place in a gendered context (Williams and Hiekes 1993). We also recognize that every understanding of the

social world is impacted by the social identities, the men as well as the authors of the study. However, in order to understand the caregiving experiences and the notions of support during these focus-group interviews, we need to address the fact that notions of support also include experiences of not being supported. Moreover, the latter are as important as the more obvious descriptions of support. This will be further elaborated in the three categories; Shrinking social life, Stoic loneliness and Reciprocity and coaching as re-connecting.

Shrinking social life

The men had shared a long relationship with their partners, some for more than 40 years and had built up a long lasting relation with each other as well as with friends and neighbours. An important issue in the men's stories is the protection of their partners and their relationships with them. In the men's descriptions, protection is prioritised over relations with other family members and friends. Caring for a partner brings with it a responsibility to protect their partners and to manage the caregiving in private. In order to do so, the men express a need to "defoliate" their own social lives in order to protect their partners from harm and shame when meeting others.

None of the men could tell when their partner relationship changed from a mutual relation to a caregiving relation, with the men taking on a primary caregiving responsibility. One of the men says;

...social life shrinks to a minimum but it doesn't happen at once, only gradually and by doing so you have the time to adjust. And you even think it's quite good that it happens...and all of a sudden...five years have passed so it doesn't come abruptly but creeps upon you.

As shown in the above quotation the shrinking social life is something that happens gradually. However, this process of a shrinking social life is described, not exclusively as a negative experience, but as something they are "letting happen". By doing so, the men express the idea that they can find time to adjust and recapitulate what is important for them in life.

The social commitments and social relations outside the family that the men were engaged in prior to caregiving are described as something that their partner had taken responsibility for building up and maintaining over the years. The men indicated that even their own friends were based on their partner's social network. For example, social relations to other men had been established over the years by husband-to-husband contacts. When their partners' illness increased, this also affected the couples' social life.

We had a circle of friends. Nothing excessive and it was mostly her who was interested in that life actually...getting invited out for dinner and taking people home, you know the usual social interactions that she really enjoyed. But she started to back off one day because she didn't have the energy to go through with it. This resulted in me having to inform our friends that we couldn't participate anymore. The effect of this has been that I sort of defoliate my own social life bit by bit; and that the old friends we used to have aren't present anymore. That is one consequence of it.

The men felt a responsibility to withdraw from social activities they had been engaged in. The withdrawal from the social life and the defoliation of the men's networks is also expressed by the men as a reciprocal agreement between the men and their partners. However something that was reflected upon during the interviews was that the men's responsibility was experienced as more difficult than most of the men had originally thought it would be. Protecting their partners from harm together with the desire to maintain independence became in the end too difficult.

I thought that I should manage the situation much better than I did. I am pretty sure I am able to manage this, I thought. But in the end, it sort of "eats its way into you" when there is no possibility to rest. It's rowdy during the nights, during the days, during the meals. It gets to you, hard.

The defoliation process is something that the men are thrown into and have to manage by gradually accepting their position as a primary caregiver in its deeper meaning "I am alone in providing care".

Stoic loneliness and miss-matching support

The primary caregiving responsibility is understood as a stoic loneliness related to the experience of the obligation to "do it all" as they verbalize it during the interviews. But when the men talk about the caregiving experience they also talk about how the experience shapes their caregiving career. They look at others differently or from a different perspective when they are improving as caregivers. One of the men says:

You can't tell anyone who hasn't been through it, they don't understand what you experienced, and you can't explain it. There are so many people (friends) that don't even cope with just visiting us for a short time. They just can't, they don't understand what's going on, that a person can act that foolish and so stupid that's just how it is.

As shown in the quotation, understanding is a key- word when the men describe their situation. Understanding is something they refer back to when they describe what support means to them. Being alone is not just a social consequence of the defoliation. It is also a state of mind due to the caregiving experience that makes them unique in relation to others and, more specific, in relation to other men.

This notion is however not described by the men when talking about the support they receive from family and friends. Instead the men describe the way that the supporting activities provided by their families often do not correspond with the men's needs. One of the men says:

I have two sons and their wives visit me with pleasure and they help me with the curtains, changing ornaments for Christmas and other things that I don't pay attention to and care so much about. But they do it anyway.

As shown in the quotation, being able to help seems to be to "keep things running" with a female presence in the household. The men describe the support they are given as highly influenced by notions of stereotyped traditional activities which do not correspond to what the men believe is important in order to feel supported. In other words, support provided by family and friends is based on the assumption that the men need help with practical household tasks while the men describe that what they need as support rather should be based on a reciprocal understanding of the life as a caregiver.

Reciprocity and coaching as re-connecting

Taking account of the men's descriptions about informal support throughout the interviews and what the men describe as the core of support, it is obvious that support for them is not related to something they only receive from others. Instead, it seems to be related to something the men give or, at least, related to a process of reciprocity with others. When being asked about what support means to the men, they immediately start to reflect about situations when they have been able to share their life situation and caregiving experiences with other men, who recently have entered a caregiving career. The men also emphasise the importance of meeting with each other at the relative centre where the interviews were conducted. However, they do not view the relative centre as a place to be educated or supported by professional care staff. Instead, it is a place where they can meet with each other and share life experiences.

And so it is that when Alfred, Sven and I talk with each other, we know what we are talking about because we are in the same situation. Leonard as well, and then when

you talk over a cup of coffee you are in it yourself and that makes it's much easier for you to talk about it.

In other words, in order to feel supported and feel recognised for the care the men provide to their partners, they express a need to meet with people with whom they feel related to, share life stories and experience reciprocity.

Reciprocity for the men is understood as being able to support other men and share experiences and advice about caregiving. However, support is not only directed towards sharing knowledge about caregiving activities, but also serves as a way to support and confirm each other's identities as men. The men still feel they have an important role, which reflects some dominant public discourses about men in relation to advising and problem solving, which leads to reciprocal recognition and support. The men in our study have, even though being retired from work force, capabilities to provide support in terms of "relevant" experiences of caregiving. During the interviews the men carefully listen to each other and frequently acknowledge and comment on each other's stories. They also provide each other with suggestions where to turn to for help or describe how they have managed a similar situation.

I have some acquaintances who recently have come into the same situation. I help them a lot with advices and I have told them that they can't go on living like they used to. They have to change their way of life, because you can't go on living like before because life is about to change and they just don't know it. They are so inexperienced about how to act in relation to this, so I support them....and by doing so, it's just like that the experience we (the men) have is worth something for them and you can support them.

Based on the above descriptions of reciprocal recognition and support, the connection to something that is familiar in men's culture and well known through sports and club activities is striking; namely the term "coaching". In coaching activities special knowledge and skills are used as guidance for those with less such knowledge and skills. In relation to caregiving, the men in our study express how they coach each other by sharing personal experiences, knowledge about caregiving tasks and guidance about where to seek formal help. The reciprocal recognition and coaching activities described are important in order to understand older men's notion of support and how they wish to pay their experiences and knowledge forward to other primary caregivers. This will be further elaborated on as the principle of "paying it forward".

Understanding the male carer

So, what is the notion of informal support for older men who enter the responsibilities of being a primary caregiver? Even though the small sample used in this study precludes any claims of generalisability, insights can be gained showing that men’s positions drastically change as a social and personal consequence of caregiving. In future studies other types of analysis, for example discourse analysis, would add important knowledge regarding older men and caregiving. As the title demonstrates, we have addressed the process of caregiving and support as a defoliation process. The characteristics of the male carer, pictured in earlier research as a stoic loner, is described but maybe not well understood. We argue that portraying the male carer as a stoic loner does not challenge hegemonic ideals but instead embraces them as well as the idea of dichotomous gender. The stoic loner becomes an essentialized character that provides a meaning to a hegemonic masculinity. Campbell and Carroll (2007) stress that many women who reject behaviours and traits associated with hegemonic forms of masculinity find it difficult to form relationships with men who do not conform to hegemonic ideals. This statement has relevance to the male caregivers in our study. The defoliation process can be regarded, firstly, as a consequence of difficulty in upholding relationships with unconventional men, but secondly, as the caregiving men’s difficulty in upholding relations with people, men and women, who embrace hegemonic ideals about masculinity and constantly question them in their situation. From this position caregiving men seem to reach out and connect with other men who share the same experiences.

In our talk with the men, the satisfaction of coaching other men who enter caregiving or being supportive in a group of significant other men is central to the men’s notion of support. In the network of men who are, and is about to become, primary caregivers, the principle of “paying it forward” or general reciprocity (cf. Van Der Geest and von Faber 2002) is an important part of men’s notion of support. Paying it forward in the meaning –I help you and you help someone else- seems, from an existential perspective, to uphold their caring experience as valuable. This pay it forward activity is interesting. Not least, since Jalmert’s study (1983) seems to suggest that Swedish men have an “in principle” attitude towards the question of equality. However, it seems always to be a personal reason why to deviate from the principle of doing “women’s work” at an individual level. When caregiving men move from words into practice they also challenge that collective “in principle” attitude and raise questions about normative constructions of masculinity which address its very foundation, namely the collective repudiation of caring practices. Thus, men’s practices and commitment to caring do not seem to relate to altruism in a wider sense but instead are connected with a position where they, on an individual level, can look upon themselves as skilled and important. One of the reasons for this might be that the men are confronted with troublesome associations between masculinity and car-

egiving which are sometimes visible in relatives' and friends' actions of support. It is these associations that the older men must constantly challenge.

Moreover, it may well be that critical studies on men's perspective (Hearn and Pringle 2006) offer additional tools for understanding the position of some of the men in this study. As we have already noted above, the patterns of men's reaction to support revealed by previous research seem strikingly similar to patterns which often seem to characterise men's reaction to seeking medical help for themselves (Hearn and Kolga 2006). Such patterns (i.e. reluctance or refusal until a point of crisis) may in some situations be linked to behaviours which in other contexts could be described as "macho" or practices which might be associated with hegemonic forms of masculinity (Hearn and Kolga 2006, Pringle and Hearn 2006): for instance, being "tough" or "hard"; expressing a belief in one's invulnerability; an unwillingness to be dependent. However, our results show that during the process of caregiving the men come to a certain point when they have to "go public" and seek support. In doing so they also address the difficulties in maintaining practices associated with hegemonic forms of masculinity. A similar interpretation may therefore also be partly relevant for some men who resist offers of support in caring situations since our study has found that these men seek support in a defined group of other men with similar experiences.

This study has drawn attention to two issues. First, problems may occur if the forms of support offered do not match the forms of support required by the men who are carers. Secondly, a greater potential for acceptance of support seems to exist if that support occurs in a frame where a degree of reciprocity is possible. Both of those issues are important in helping us to potentially understand the relationship between men carers and support in more complicated and sophisticated ways.

Yet, even as we say this, we need to add a further level of complexity to the picture. For, there are still various ways of interpreting that second issue i.e. that some men carers welcome support more readily if it is provided within some kind of reciprocal arrangement. As we have noted, on the one hand, we can interpret such a response as part of a more generally desire by service users for a degree of reciprocity in their dealings with support-givers (state agencies, NGOs or other individuals). On the other hand, we find it useful to partly interpret this emphasis on reciprocity among men carers through the lens of gender. For in some cases it may well be that the desire for reciprocity to a certain extent arises – again – from a particular reluctance among men to be seen as dependent or "weak" or "helpless". Links to hegemonic ways of being men may still be present in such cases. At the same time, it is important that one does not interpret the patterns of response by all the men in this study purely through the lens of gender: to some extent, their adhesion to principles of reciprocity can simply be explained by the fact that many informal carers – of either gender – general appreciate opportunities for reciprocity in the forms of welfare delivery they experience. In our talks with caregiving men it is obvi-

ous that the social consequences of caring radically challenge the men's values and ideals. In the process, they both sometimes have to accept and sometimes even welcome the stocic loneliness that becomes the consequence of caring. So the lonely road framed by Green Day in their song has to be understood as a process of mastering instabilities in life that both challenge hetronormative and patriarchal ideals.

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