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# HEALTH AND WELL-BEING IN SOCIAL CARE WORKERS

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## Abstract

In recent years research attention has focused on social care services, in particular the range and extent of informal care. This research interest can be seen to occur in the context of the movement within health policy toward community based care. The vast majority of carers, both informal and formal (i.e. paid) are women. Research findings, particularly on informal carers indicate vulnerabilities in their physical and mental health and that care, for the most part, is unshared by other family members and inadequately supported by statutory health services. This paper discusses the marginal status of care-work, with particular reference to the gendered nature of social care. How this contributes to the compromised health status of carers and inadequate support services is discussed, drawing from both international studies and those conducted in the Irish context. Recommendations are made in relation to improving the quality of life, health status and working conditions of carers.

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## Introduction

Social care has been defined by Fahey as care that takes place in the home or an 'institutional setting which is a substitute for home for those who have become too dependant to live in the community'.<sup>1</sup> Although not inaccurate, this definition does not quite capture the range and extent of social care in Ireland. A broader definition of social care might be more appropriate, in that front line workers who work with homeless people, who work in day care centres for older people, and who work with community-based support services for various client groups can also be termed social care workers. Social care can include medical care, but is chiefly characterised by personal and social services. Fahey points out that these can be and usually are provided by family members.

Those in receipt of social care are a heterogeneous group, but older people, persons with a learning disability and persons with mental health difficulties would be the most common client groups. Carers who are in paid employment are often termed 'formal social care workers', while those who provide care to family members or relatives, are termed informal or family carers.

Family members who provide informal care have been the subject of research attention in recent years and a limited number of studies have been carried out on formal social care workers. Through the research literature on social care, there are three phenomena that appear with remarkable consistency. Carers, be they family carers or paid workers, or both, are usually women. Their mental and

physical health is typically compromised when compared to matched samples of persons without onerous care responsibilities. Care is unshared by relatives, i.e. the carer has sole responsibility to a significant extent, and carers consistently report inadequate back-up or support from the formal health services. The following discussion will examine these three aspects of social care in more detail, and attempt to consider how the gender specific nature of social care contributes to the compromised health status of carers and inadequate support services for carers. While reference will be made to international studies, more detailed examination will be given to studies conducted in the Irish context.

## Policy Context

Research interest in social care can be seen to occur in the context of the movement within health policy toward community based care, in both the UK and Ireland. Community care is, by now, a familiar concept in health service planning. The past 20 years have seen a shift in emphasis from the provision of care by voluntary agencies toward the supportive role that voluntary agencies can play in relation to family based care.<sup>2</sup> This trend has evolved against a background of concerns regarding the growing costs of residential care and accompanying cut backs on spending in the health sector, concern with the quality of care found in institutions, and demographic trends which predict increases in the numbers of persons in the community who will require care.<sup>3</sup>

In relation to the care of older people in Ireland, a development of a community care policy can be traced from the 1951 *White Paper* through to the present policy document from 1994, *Shaping a Healthier Future*.<sup>4</sup> Policy statements and recommendations regarding services for people with learning disabilities and people with mental health problems also endorse an increase in community based care. These various documents advocate a shift from institution based care to community based care, an upgrading and expansion of social care services, and recommendations that families should be facilitated by the State to maintain their relatives at home. The policy document *The Years Ahead*<sup>5</sup> acknowledges that families caring for older relatives receive little recognition and support. *Shaping a Healthier Future* contains explicit objectives to maintain older people in dignity and independence at home, independent living and community based care being described as the most desirable option, with residential care only as a last resort. Hence, additional objectives refer to encouraging and supporting the care of older people in their own community by family, neighbours, and voluntary organisations in every way possible. Thus it is clear that State policy in this area:

firmly subscribes to the need for support services of carers of elderly people living at home ... but also that ... a policy of community care is dependent on the willingness and availability of family members to provide care.<sup>6</sup>

This of courses translates into the willingness and availability of women to provide care, in that the term community care frequently obscures the reality that women typically provide care in the community.<sup>7</sup>

## Informal Carers

Carers, where once invisible, have become a legitimate topic of discussion in public policy debate, especially in relation to support services.<sup>8</sup> In the international context, research has been conducted on who within the family provides such care,<sup>9</sup> the nature of care and of caring,<sup>10</sup> the range and extent of care,<sup>11</sup> support for informal carers,<sup>12</sup> the 'burden' of care,<sup>13</sup> and the social, psychological and physical consequences of the provision of care.<sup>14</sup>

A limited number of studies have been carried out in Ireland. The first nationally representative study to be conducted on informal care was commissioned by the National Council for the Aged, and addressed a number of questions about the range and extent of informal care given to older people in Ireland,<sup>15</sup> and about the caring process.<sup>16</sup> Further studies have added to these findings.<sup>17</sup>

However, despite the availability of research studies, it is hard to find an accurate definition of informal care that really captures its essence; the range and extent of care duties, the caring process, the financial and emotional costs of care and the psychological and emotional rewards attached to care. The work of Ungerson probably best describes the nature of informal caring.<sup>18</sup> In 1987, in 'Policy is Personal', she reported findings from in-depth interviews conducted with 19 informal carers in which she explored their feelings, both positive and negative, about caring; how they came to be the carer within the family network, the reasons they gave for caring, and the process of caring. In this, Ungerson draws a detailed picture of the life of a carer, the multi-faceted nature of care and the complexity of it, much of which escapes the more tightly controlled experimental studies. Ungerson finds that caring is something that is complex in that it is often contradictory. Caring involves considerable 'moral' decisions, is strongly bound up with ideas of duty and obligation embedded in kinship bonds and power dynamics within families. It also is associated with both deep satisfaction and grim anger, feelings of contentment and feelings of despair. Very few studies on informal care discuss the fact that care is a gendered phenomenon, with the notable exception of the work of Finch and Groves, Ungerson, and Baldwin and Twigg.<sup>19</sup>

## Formal Social Care Workers

Less research has been conducted on formal social care workers than on informal carers. Virtually no studies have been conducted on nurses' aides, and very few studies have been carried out on the personal experiences of formal social care workers, or have compared the health status of formal care workers with other health care workers, non-care workers or informal carers. Work on the Home Help Service in the UK has been carried out by Hedley and Norman, and Bebbington and Davies.<sup>20</sup> A survey of home care services in Europe has been conducted by Hutten and Kerkstra.<sup>21</sup> The only comprehensive research study on the Home Help Service in Ireland was carried out by Lundstrom and McKeown.<sup>22</sup>

However, any real dichotomy between formal and informal care is questionable, and the distinction has been challenged, both in the context of the movement towards use of carer allowances to pay family carers,<sup>23</sup> and the proliferation in the UK of 'paid volunteering' schemes mentioned by Baldock and Ungerson.<sup>24</sup> Baldock and Ungerson report that some paid volunteering schemes pay tiny amounts, despite carrying a heavy work load for the carers, and comment on the frequency with which the workers take on additional duties which are not part of their brief and are not linked to extra pay. Similarly, Lundstrom and McKeown found evidence of home helps 'spending far more time and performing more tasks for their clients than their job specified', and that the nature of extra tasks included both practical tasks, care and support.<sup>25</sup>

Further evidence to support the blurred distinction between 'formal' care and informal care comes from the finding that many home helps are also informal carers or have been informal carers. Lundstrom and McKeown report that over 60% of their sample of home helps currently care for or have cared for an infirm relative. Personal experience of the authors of this paper, in the recruitment of carers to training courses, indicates that a large proportion of formal social care workers have been or continue to be informal carers.

## Gender and Care

Across a wide range of studies on informal care, it emerges that approximately three quarters of informal carers are women.<sup>26</sup> Yoder, Yonker and Leaper, discussing paid care workers, comment that these are usually women.<sup>27</sup> In Ireland, Lundstrom and McKeown reported that almost all home helps are women. In addition to this, female informal carers are more likely to be providing informal care to highly dependent older people, are more likely to live with their care recipient and hence are therefore more likely to have to cope with increased dependency. Women assume more of the intensive caring than men<sup>28</sup> and male carers are more likely to be employed than female.<sup>29</sup> Ungerson found, in her admittedly small sample, that male carers are typically spouses, whereas the women carers provided informal care to spouses, parents, parents-in-law, aunts, uncles or neighbours.

## The Nature of Care and The Costs Of Care

The heavy demands of care and the stressful nature of care are well documented. Although generally not perceived as an entirely negative experience,<sup>30</sup> the majority of studies on the provision of care within families and the community, find that it involves considerable hard work, physical strain and emotional resources. [For a more detailed discussion on women as health care workers in primary and family care context, see Anne MacFarlane in this volume]. By its nature it is continuous, usually progressively demanding, and can be very frustrating, especially in the case of providing care to a relative with a confusional disorder such as Alzheimer's disease. For 20% of carers of older people, caring is a 24 hour commitment, and for a further 35% it involves eight hours a day.<sup>31</sup>

Blackwell *et al.* reported that carers work an average of 58 hours per week, substantially more than the average industrial working week.

The 'costs' of caring are also reasonably well documented. Irish research has found that 53% of carers of older people are confined to home for 5–10 hours a day, 59% cannot leave the older person alone, and that visits to friends decrease with caring commitment.<sup>32</sup> In a study on carers in the West of Ireland, Keane found that 32% of carers had been providing care for periods from 11 to 40 years. Many studies on caring find self-reported stress, loneliness, isolation and difficulties with coping on the part of carers. These findings are supported by studies in which comparisons are made between carers and matched samples of community residents not providing family care.<sup>33</sup> In Ireland, one third of carers of older people experience high levels of strain,<sup>34</sup> and 29.5% of carers of dependant elderly scored over the cut off point for psychological distress, using the General Health Questionnaire.<sup>35</sup> This is well above the proportion of national sample scoring above the cut off point i.e. 16.2%. Carers are also found to suffer in terms of reduced social interaction,<sup>36</sup> and 24% of carers of older people reported adverse effects on family relationships.<sup>37</sup>

In relation to physical well-being, there is ample evidence that carers have compromised health status.<sup>38</sup> Twenty two per cent of carers of older people in Ireland rate their health as poor, 33% have an on-going health problem, and one third feel their health has suffered because of caring demands.<sup>39</sup> In the study conducted on carers of dependant elderly, 46% were found have high scores on a measure of 'physical strain'.<sup>40</sup>

### Support for Carers

Despite such a heavy demand on the personal resources of carers, those who provide care for family members or in the community get very little back up and support from others, either informally or from health professionals. Just half of the sample of carers of older people interviewed by O'Connor and Ruddle reported that although quite frequently visited by other family members, they received very little practical support. Nissel and Bonnerjea, in their study of women caring for elderly disabled relatives, similarly found that other family members did not provide a lot of support. It is consistently reported in the literature that support and back-up from health professionals which could supplement care given informally by relatives, is either poor or non-existent.<sup>41</sup> Keane found that only 23% of carers in the West of Ireland received support from health personnel. O'Connor and Ruddle estimate that 69% of carers of older people receive low levels of support from formal services. Finucane *et al.* also found in their study on support for carers that there is very little in the way of formal support. They found that community-based and hospital services were over-stretched, priorities in assigning services were medical not psychological, day-centres were poorly funded, and often services are withheld on the basis of a carer being present.

In relation to financial support, Larragy found that less than 10% of live-in carers get the (means tested) Carer's Allowance, and less than half of these receive the full allowance. It is worth noting that in Ireland, formal social care services, i.e. the Home Help Service, are discretionary within the health boards. These are often allocated on a substitutional basis i.e. they are withdrawn or reduced if a family member is available to provide social care, thus extending home based care, often regardless of the carer's stress level. Additionally, within the Home Help Service, Lundstrom and McKeown reported that no formal mechanism exists in the service for replacing home helps when they are ill, even if hospitalised. Not surprisingly, some 'soldier on, even when ill'.<sup>42</sup> Some home helps in their study worked seven days a week in the absence of a back up service.

## Discussion

The research findings thus far, present a fairly miserable picture of social care in Ireland. Demanding physical work, sometimes around-the-clock responsibilities, emotional drain and strain and increasingly limited opportunities to maintain a social life or to look after one's health. This is set against a background of possible family tension, juggling the emotional needs of family members and little or no recognition of the need for support in the form of back-up, respite or financial, by the State health services. It is important, however, to draw a distinction here between 'care' and the 'provision of care' under certain conditions. Care, in and of itself, is not necessarily a negative experience. Both Ungerson and Lundstrom and McKeown comment on the feelings of satisfaction and pleasure many carers derive from caring. What is negative about caring, it seems, is the conditions under which people find themselves working and the assumptions that underpin their delivery of a care service. Lundstrom and McKeown report for example, that while the majority of the home helps they interviewed spoke of genuine dedication and commitment, they felt that the service was undervalued and under-resourced. For example, they felt that:

... their dedication to their clients precludes them from withdrawing service but causes bitterness as they believe the health boards know this and exploit them.<sup>43</sup>

Ungerson reports that the carers she interviewed in her study were 'rather sorry that they had become carers'.<sup>44</sup> She felt that, on balance, there was a deep unhappiness about informal care, and that her interviewees typically felt that care 'should be paid for and should never devolve on a single person as it had done on them'.<sup>45</sup>

That heavy demands are placed on carers in the absence of cohesive and reliable support structure is clearly related to the fact that most carers are women. Care is predominantly undertaken by women because of powerful material and ideological forces that determine that they will do so. Ungerson argues that as long as women have an inferior position in the labour market—both in terms of access and equal pay—within the family, their paid work is seen to be more

dispensable and less critical to the family's financial status. When, within a family there is a need to provide care, women seem to be the 'logical' option to either reduce their paid work or give it up altogether to provide this care. In such situations, Ungerson argues, the ideology of a woman's place being in the home, engaged in caring duties, is reinforced and thus the twin forces of the labour market and ideology interact.<sup>46</sup>

Although written fourteen years ago, at a time when women's labour market status was poorer than it is today, this labour market argument is not as dated as it might sound. The participation rate of women in the labour force in Ireland has increased from 28% in 1971 to 35% in 1995, although this is still substantially lower than the participation rate for men (69%). More than half of both the part-time work force and occasional work force is female. There is still a large gap in the hourly wage rate between men and women, and little progress has been made in Ireland since the 1980s.<sup>47</sup> Despite this, of the two forces of labour market and ideology that Ungerson discusses, that of ideology is definitely the more significant. Labour market effects may explain why women become the carers in a family setting but they do not explain sufficiently why informal care receives little State support or back up or why formal social care services such as the Home Help Service are discretionary and poorly resourced.

Turning then to the force of ideology, as conjectured here, which is chiefly responsible for the marginal status of care work, it must first be acknowledged that caring is not just 'something that women do', as part of the expected array of sex-role behaviours or as 'an outcome of the sexual division of labour within the family'.<sup>48</sup> Caring is intricately bound up with definitions and conceptions of femininity in such a way that, Graham suggests, it is used to differentiate one sex from another. Caring is thought to be part of a woman's self-identity and an intrinsic part of her 'feminine nature'. To be a woman is to 'care', while 'not-caring' but 'doing' (i.e. 'productive' work in the commercial world) is the defining characteristic of manhood. By this token, a woman who does not want to provide care or seem to feel fulfilled by caring, somehow has her femininity and 'essence' questioned. What Graham is saying is that caring underwrites women's self identity at a profound level.<sup>49</sup>

This is not to endorse the position that caring is essential to womanhood, a position that would reinforce the status quo.<sup>50</sup> Definitions of femininity and the location of caring within it, are of course socially constructed. Graham is careful to point out that women's dependant status in society is determined by economic forces in addition to these 'psychic' forces.<sup>51</sup> However, the fact remains that caring has become embedded in constructions of femininity and womanhood and that this creates the powerful ideological force which results in women becoming primary carers within the family and the community. Graham concludes that:

... the experience of caring is the medium through which women are accepted into and feel they belong to the social world. It is the medium through which they gain admittance into both the private world of the home and the public world of the labour market. It is through caring in an informal capacity as mothers, wives, daughters, neighbours, friends, and

through formal caring—as nurses, secretaries, cleaners, teachers, and social workers—that women enter and occupy their place in society.<sup>52</sup>

It is easy to see how this ideology influences the ‘selection’ of women within family networks to provide care. However, it is also evident that it influences the compromised health status of informal carers and the poor working conditions of formal social care workers. From the assumptions that care is ‘natural’ for women, follows the corollary that it is not really legitimate ‘work’, and that, somehow, women absorb their caring duties into their daily activities. In this climate, the strain and drain of care is not adequately acknowledged. More essentially, as Ungerson notes, ‘the operation of gendered expectations and obligations’ leads to the carer’s ‘own needs becoming subordinate to the needs of someone else’.<sup>53</sup> Health needs therefore, can easily be set aside in the interests of the needs of the elderly or disabled person who is the recipient of care.

Similarly, the assumptions about the naturalness and essentiality of care to being a woman, isolate women carers from back-up services that could be provided from the health services. There is evidence that male family carers are more likely to receive support than female carers. Yoder *et al.* report that male carers are more likely to have the person they care for received into an institution. They further note that those cared for by men, who are taken into long stay care, are more able than those cared for by women. Male carers are more likely to receive services such as home helps, meals-on-wheels, rehabilitation, assessment and long stay care. Women carers, on the other hand, are more likely to receive day-care and short stay care.<sup>54</sup> The assumption seems to be that once there is a woman present, the State can largely absolve itself of any further responsibility.

Finally, when care is delivered in the community through Home Help Services, personal care assistants, meals on wheels, etc. it suffers again from the ‘women being natural carers’ ideology. The very fact that the Home Help Service in Ireland is discretionary is evidence in itself of the influence of these ideas. The health boards are empowered, but not required, to provide a Home Help Service. As there is no legal requirement, there is nothing to prevent a health board from reducing the funding it directs to the service, or withholding the service altogether.<sup>55</sup>

Further evidence comes from objection to the idea of training home helps. There is considerable resistance within the health boards in Ireland to training home helps, on the grounds that training would result in ‘over-professionalisation’, would undermine the voluntary or ‘caring about’ quality of their work and devalue its ‘good neighbour’ dimension.<sup>56</sup> In relation to the low wages formal care workers are paid, Baldock and Ungerson have argued that the rationale of nominal and ‘tiny’ amounts of pay for care work has the explicit intention of leading carers to take on additional work. Their argument is that nominal pay for care work locates it along a continuum of family to neighbourly care, where the locus of care is originally within the family and thus the motivation is love, not greed. It is hard to avoid the connection here between this and the fact that previous informal care in the family is sought when recruiting home helps.

## Health Promotion for Social Care Workers

There are several issues at stake here. Firstly, there is the issue of exploitation of women as workers, both within the home and the community. Secondly, there is the issue of poor health status within a segment of the community. Thirdly, there is the issue of health policy and policies relating to the development of community care in particular. As discussed, it is clear that these all stem from the root problem of the social construction of care and caring as being essentially female.

In practical terms, several measures could be taken to improve the quality of life of the carer and contribute towards a more structured organisation of community care. In this light, the following recommendations are made:

- (a) A legal mandate to provide Home Help Services in every health board, and designated funding to develop the service adequately as recommended by Lundstrom and McKeown, would improve working conditions of home helps.
- (b) The recruitment practice and in particular the assumption that those who have provided care informally are best suited to work as a home help could bear scrutiny and revision. While 'informal carers' might indeed be suitable in many ways to perform home help duties they may also be the most 'exploitable'.
- (c) Co-ordination of the various types and grades of social care worker (e.g. home helps, personal care assistants, personal assistants, respite workers, primary health care workers, family liaison workers) across all health boards with a view to clarifying and developing appropriate pay scales and working conditions.
- (d) This, in turn would permit examination of what education and training is required for the various types of worker and the development of a cohesive ladder of educational and career progression. While it has been argued that making community care more structured and 'formalised' could lead to the further exploitation of carers, the position taken here is that it is in a climate of 'informality', 'ad hoc-ery' and lack of consistency (between health boards, for example) that notions about the appropriateness of paying minimal wages for care work (or not paying care work at all), flourish.
- (e) Finally, for those who opt to care in the family, it is essential that adequate community supports are put in place. This would include large scale availability of respite workers and appropriate funding for the development of day care centres.

Therefore, in order for social care to be recognised as legitimate work, to be paid well and adequately supported by health care services, and for the health of carers to improve, this ideology that caring, and therefore care work, is part of a woman's 'natural' identity must be seriously challenged and deconstructed. As

long as this remains unchallenged, community care will continue to translate into 'woman-care' and the exploitation of women in care work will remain obscured and concealed.

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