

Review

Applying Risk Society Theory to findings of a scoping review on caregiver safety

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What is known about the topic

- Chronic illnesses are a major societal concern and most care is provided by family caregivers.
- In 2006, Lang and Edwards revealed that the health and safety of the home-care client were linked to those of the caregiver.
- Little is published about safety in home care and in particular, the safety of the caregiver.

What this paper adds

- Identification of four safety markers: conscription, economics of caring, abuse, and caregiver as hidden patient.
- Initiation of a dialogue on the location of risk and safety.
- Application of Risk Society Theory to markers of caregiver safety in an attempt to illustrate how risk is constructed in society and implications for health-care and ultimately, caregivers.

Abstract

Chronic illness represents a growing concern in the western world and individuals living with chronic illness are primarily managed at home by family caregivers. A scoping review of the home-care literature (2004–2009; updated with review articles from 2010 to January 2013) on the topic of the caregiver revealed that this group experiences the following safety-related concerns: caregivers are conscripted to the role, experience economic hardship, risk being abused as well as abusing, and may well become patients themselves. Methodology and methods used in the scoping review are presented as well as a brief overview of the findings. The concepts of risk and safety are defined. Risk Society Theory is introduced and used as a lens to view the findings, and to contribute to an understanding of the construction of risk in contemporary health-care.

Keywords: caregiver, chronic illness, home care, risk, Risk Society Theory, safety

Introduction

Chronic illness is a rising healthcare concern across the Western world. In excess of 20 million people in the United Kingdom (UK) suffer from one of five chronic illnesses (Alder *et al.* 2005). In the United States of America (USA), an estimated 133 million Americans have at least one chronic illness (Wu & Green 2000) and 90.5% of Canada's 4 192 000 seniors report at least one chronic condition (Turcotte & Schellenberg 2006, Canadian Home Care Association 2008). Chronic illness necessitates a great deal of care, the majority of which is provided by family caregivers. Estimates of the numbers of caregivers providing unpaid care to individuals living with chronic illness in the UK, USA and Canada are 6 440 713; 10 000 000 and 4 000 000 respectively. These family caregivers may still be in the workforce, are more likely to be women and are themselves ageing [Canadian Caregiver Coalition (CCC) 2008, 2010, Buckner & Yeandle 2011, The MetLife Study of Caregiving Costs to Working Caregivers 2011]. These same countries are also projecting an exponential rise in the numbers of seniors in their respective populations. For example, by 2036, the number of Canadians 65 and over may double, potentially outnumbering children, a historical first (Statistics Canada 2009) with seniors making up approximately 25% of the population. These projections are highly indicative of the future demand for unpaid caregivers and the importance of growing our knowledge and understanding of the caregiver experience (Canadian Institute for Health Information 2010). In this manuscript, the caregiver is considered to be the person providing care at

home in an unpaid capacity to a family member, friend or someone to whom they are close, and without which the client would not be able to manage on their own.

Lang and Edwards (2006) conducted interviews with key informants in home care and reported that in the home-care setting, institutional perspectives on patient safety were not to be unilaterally applied, that the family, and not simply the home-care client, must be considered as a unit of care and that the health and safety of the home-care client were completely intertwined with those of the caregiver.

Acting on these findings, this research team conducted an environmental scan of safety in home care in Canada and found that home-care clients were preoccupied with the health and well-being of the caregiver and clearly realised that their remaining at home was contingent upon the caregiver (Lang *et al.* 2009). Despite this, little is published about safety in home care and in particular about the safety of the caregiver. At the same time, the home-care literature is vast and was believed to contain evidence of safety-related caregiver issues not necessarily presented as such, prompting the team to undertake a scoping review of the home-care literature to identify patterns in the data with implications for caregiver safety. The patterns identified were: conscription, economics of caring, abuse and the caregiver as a hidden patient. Full details of these patterns are available on the Canadian Patient Safety website <http://tinyurl.com/99z5dal>. Safety in home care has yet to be defined. Safety in institutional care is largely defined as 'patient safety' and has numerous definitions including the prevention of errors and adverse effects to patients associated with health-care (World Health Organisation 2012).

The aim of this study was to outline the scoping methodology and methods used in the study, describe the analysis, present the patterns identified, link safety and risk, introduce Risk Society Theory (Beck 1986), discuss the patterns in relation to the theory and provide concluding remarks.

Methodology

Scoping reviews are exploratory in nature and aim for breadth rather than depth on a topic. Scoping reviews define what is assessed and to what extent, and include all research methodologies. The scoping review typically does not begin with a defined question like the systematic review. The area of interest for this scoping review was the caregiver and their safety within home care. We remained open to as much home-care literature as possible to avoid missing work considered highly relevant to the topic. The

framework articulated in Arksey and O'Malley (2005) and Grant and Booth (2009) was employed to guide the review and included five stages: (1) identifying the research question, (2) identifying relevant studies, (3) study selection, (4) charting the data and (5) collating, summarising and reporting the results.

Question: What evidence does the home-care literature related to caregivers hold that may be deemed relevant to caregiver safety?

Identifying relevant studies: This stage involved a search of databases that included the Cumulative Index to Nursing and Allied Health Literature (CINAHL), PubMed-Medline, EMBASE, PsychINFO, Sociological Abstracts, Cochrane Database of Systematic Reviews, Dissertation Abstracts International, Up-to-Date and Web of Science. Data sources and search terms are outlined in Boxes 1 and 2.

Study Selection involved developing inclusion/exclusion criteria (Box 3) and a three-stage screening process. All studies involving unpaid caregivers across the lifespan; published between 2004 and 2009; conducted in Australia, Canada, Denmark, Finland, Israel, Norway, Sweden, United Kingdom (England, Ireland, Scotland, Wales) and United States; in English or French; across all illness conditions; regardless of research design, documents published by the government of Canada or Associations related to home care were retrieved. Literature regarding settings such as hospice, nursing homes, shelters, assisted living or convalescent homes was excluded. In preparation for publication of the findings of this scoping review, and to determine if the findings remained current, a search of the home-care literature using the original strategy was conducted for review articles from 2010 to January 2013. Ten articles were located, five of which were systematic reviews. The results in eight of these articles reflected the findings of this scoping review and were included in the text references to support the identified patterns. The two remaining reviews addressed cost-effectiveness of interventions to support caregivers (Jones *et al.* 2012) and the effects of assistive technology for caregivers (Mortenson *et al.* 2012). Results reported that little evidence of cost-effectiveness of interventions was found and that the evidence is inconclusive on the effects of assistive technology.

Screening process

Two library information specialists conducted the search using a combination of controlled vocabulary and keyword searches. Keywords from Box 2 were mapped onto subject headings from Medical Subject Headings, Library of Congress Subject Headings and CINAHL. These subject headings together with the

Box 1 Data sources for literature review

Electronic bibliographic databases searched

Biznar
 Cumulative Index to Nursing and Allied Health Literature
 Cochrane
 Dissertation abstracts
 eBrary
 EMBASE
 Medline/PubMed
 PsycINFO
 ScienceResearch Sociological Abstracts
 Social Science Research Network
 Social Services Abstracts
 Up-to-Date
 Web of Science

Grey literature searched

Canadian government websites
 Professional Associations websites
 Publications from Key Canadian Home Care Researchers

Box 2 Keyword search terms

- (a) Setting
 Home care
 Home nursing
- (b) Individuals in caring relationship
 Caregiver
 Carer
 Client
 Family
 Patient
- (c) Health and illness subject areas
- | | |
|--------------------------------------------------|------------------------------------------------------|
| AIDS/HIV | |
| Alzheimer's (falls) | Frail or vulnerable elderly/
diminished capacity |
| Anxiety/fear/hope/invisible | Medication/diversion/
polypharmacy |
| Cancer | Mental health/illness
(psychological/psychiatric) |
| Caregiver burden | Paediatrics |
| Congestive heart failure | Quality of care/quality of
health-care/safety |
| Chronic disease (management/
risk management) | Renal failure |
| Chronic obstructive
pulmonary disease | |
| Dementia | Respite care |
| Depression | Stroke |
| Disabled/handicapped
(children) | Technology |
| Elder abuse/abuse | |
| End of life/palliative care/
terminal care | |
| Evidence-based approach/
best practice | |

inclusion and exclusion criteria (Box 3) were used to retrieve literature from the target sources. The initial search produced 1672 titles and at this point, a ranking system was instituted to guide the three stages of title, abstract and full document review. The rankings

Box 3 Criteria guiding the selection of literature

Inclusion

All studies involving unpaid caregivers across the lifespan
 Published between 2004 and 2009, updated with review
 articles from 2010 to January 2013, in English and French
 Across all illness conditions
 Including all research designs
 Published in Australia, Canada, Denmark, Finland, Israel,
 Norway, Sweden, United Kingdom (England, Ireland, Scotland,
 Wales) and United States
 Documents published by the Government of Canada or
 associations related to home care

Exclusion

Literature regarding settings such as hospice, nursing homes,
 shelters, assisted living, and convalescent homes

assigned were relevant, potentially relevant and not relevant. At each stage, all of the material was examined by two reviewers to reach consensus. If consensus was not reached, a third reviewer was consulted to determine the relevance of the item. Following title review, 1225 documents remained, following abstract review, 292 remained and following full text review, 107 documents were deemed relevant and retained for data extraction.

Charting the data involved the preparation of a data extraction template for each of the 107 studies with the following categories: author, year, research purpose, methodology, results and relevance of the findings to caregiver safety.

Analysis

Collating and summarising represented the analysis phase of this work. All of the literature retained was synthesised by at least two reviewers. The researchers then employed interpretive description methods to analyse the findings. Interpretive description is a qualitative research methodology intended for the study of phenomena of clinical interest, and findings are constructed and contextual (Thorne 2008). This means that the researcher is the instrument and therefore these findings represent a construction by the researchers in interaction with the data retained for the purposes of the scoping review. The researcher using Interpretive Description aims to generate solutions to everyday clinical problems or the 'how to'. The use of theory in this paper (Risk Society Theory) is intended to theorise about how the phenomenon under study, caregiver safety, is constructed in society at large. Data analysis was conducted on the findings of all included studies and the extracted statements of relevance of findings to caregiver safety. These data were coded, codes were examined and grouped to identify patterns and outliers, as well

as the relationship among patterns. Patterns identified were deemed to be relevant to caregiver safety. Outliers or instances in the data that did not represent a pattern but raised questions were examined for their ability to inform the identified patterns and to optimise opportunity for inclusion of all data in the analysis. The four caregiver safety-related patterns identified were conscription, economics of caring, abuse and the caregiver as a hidden patient. A description of what was meant by each pattern follows.

Findings

Conscription

The dictionary definition of conscription is 'compulsory enrolment of persons especially for military service'. Even though the term conscription was not used in the literature reviewed, the authors of this scoping review were left with the impression that families had little or no choice related to taking on the care-giving role. Thus, our analysis led us to describe this pattern as conscription. Families, although often reluctant to take on the caregiver role (Bigony 2007, Metier & CBC 2010; updated search of review articles completed January 2013), found themselves in a situation where someone was expected to take care of the person in need (Dow & McDonald 2007, Hearson & McClement 2007, Duxbury *et al.* 2009). In doing so, these family members reported feeling trapped, confined (Bertrand *et al.* 2006) and duty bound (Bigony 2007, Gräßel & Adabbo 2011). The expectation to take on the caregiver role largely arose at the point of discharge from hospital where a level of taken for granted exists although minimal preparation for assuming the required care is provided (Dow & McDonald 2007, VON Canada & The J. W. McConnell Foundation 2007, Docherty *et al.* 2008, Stevenson *et al.* 2008, Hudson & Payne 2011, Innes *et al.* 2011, Thinnes & Padilla 2011, Llanque & Enriquez 2012).

In addition to feeling ill prepared to take on a care-giving role, family caregivers reported that healthcare professionals made the decisions about the support services needed by caregivers, and that the services offered frequently failed to meet their needs (Sherwood *et al.* 2004, Sharpe *et al.* 2005, Neufeld *et al.* 2007). Family caregivers assumed the caregiver role under less than ideal circumstances, contributing to their feeling a lack of control in the situation (Vallerand *et al.* 2007, Munck *et al.* 2008) as well as experiencing feelings of powerlessness and helplessness (Milberg *et al.* 2004). The combination of implied compulsory enrolment, lack of preparedness for the

care-giving role, inadequate support and resultant loss of control jeopardises the safety of home-care clients and their caregivers.

Economics of care-giving

The unpaid work of caregivers saves the healthcare system billions of dollars. Estimates of unpaid care costs for Canada, Australia, and the USA respectively were 5 billion (CCC 2008), 30 and 133 billion (Spector & Tampi 2005). These savings to the healthcare system are being borne by family caregivers and at significant personal cost. These costs included giving up work (Moskowitz *et al.* 2007, Young *et al.* 2008), possible job loss, requesting to work fewer hours to provide the care required (Raina *et al.* 2005, Spector & Tampi 2005, Rose 2006), changing jobs and accepting lower pay, all to give them the flexibility necessary to provide care (Hawranik & Strain 2007). Along with the reduction in earning capacity came the need to purchase home-care supplies and equipment not covered by home-care programmes or insurance plans (Winkler *et al.* 2006).

The majority (80%) of family caregivers are women, a quarter of whom are still in the workforce and must balance work with family responsibilities and the care of an older person. Unpaid care-giving impacts the future income and financial security of the caregiver as they are less able to accrue savings or participate in employer pension plans to the extent necessary for future income security (Armstrong-Esther *et al.* 2005, Ranmuthugala *et al.* 2009). The stress associated with the economic drain that caregivers experienced impacted the emotional safety of caregivers, in that economic worries placed them at risk of developing future health problems.

Abuse

Abuse has been variously defined and for the purposes of the review was defined as follows:

A single or repeated act or lack of appropriate action occurring within any relationship where there is an expectation of trust which causes harm or distress to an older person. Abuse may be physical, psychological, sexual, financial, neglect related, medication related, abandonment, scapegoating, and marginalization. (World Health Organisation 2006) (page 1)

The forms of abuse most frequently reported in the literature were psychological (25%) and physical (5%–6%) and were described as originating with both caregivers and clients (Beach *et al.* 2005, Cooper *et al.* 2009).

Typically, a set of characteristics accompanied the perpetrator of the abuse. In situations where the

client was the abuser, they often suffered from cognitive impairment, (Beach *et al.* 2005) or dementia (Cooper *et al.* 2009). If the caregiver was the abuser, they often reported a rising burden of care (Selwood *et al.* 2009), physical health problems or depression (Beach *et al.* 2005), abused alcohol (World Health Organisation 2006) or were found to be experiencing cognitive decline (Miller *et al.* 2006). The presence of abuse was considered a cogent safety issue for all involved.

Hidden patient

Hidden patient was chosen to describe the caregiver safety-related pattern that was ubiquitous in the literature, illustrating the multitude of health concerns experienced by individuals in the caregiver role. The entire list is too lengthy to be included here; however, the psychological well-being of caregivers is well documented, including depression, decline in mental health, increased psychiatric morbidity as well as anxiety (Given *et al.* 2004, Lindsay & Anderson 2004, Garand *et al.* 2005, Mahoney *et al.* 2005, Pirraglia *et al.* 2005, Spector & Tampi 2005, Croog *et al.* 2006, Hash 2006, Schulz *et al.* 2006, Chubinski 2007, O'Rourke *et al.* 2007, Swore 2007, Fletcher *et al.* 2008, Molyneux *et al.* 2008, Rowe *et al.* 2008, Thompson *et al.* 2008, Ranmuthugala *et al.* 2009, Rivera 2009, Vitaliano *et al.* 2011, Northouse *et al.* 2012, Wang 2012). The range and extent of psychological symptoms experienced by caregivers were a pattern easily identified in the data.

Inextricably linked to psychological well-being of caregivers was their physical well-being and many suffered a variety of symptoms including back problems, migraines, coagulation and digestive system difficulties (O'Rourke *et al.* 2007, McLennon 2008, Mills *et al.* 2009). Coupled with this, caregivers were sleep-deprived due to client agitation, incontinence or wandering (Molloy *et al.* 2005, McCurry *et al.* 2007, Rausch *et al.* 2007, Rowe *et al.* 2008, Mills *et al.* 2009, Rittman *et al.* 2009, Northouse *et al.* 2012). Contributing to psychological and physical compromise is the isolation from family and friends (McCurry *et al.* 2007) and the need to continue to assume increasing responsibilities as client health declines. The increased likelihood of caregivers losing their health in the care of another meant that they may not have been well enough to care for the individual who was already ill creating a safety concern and were rapidly moving towards becoming patients themselves.

Earlier in this manuscript, under methodology, we emphasised that part of the analysis was linking the patterns, and the following statement illustrates these linkages. When caregivers feel conscripted to care for

those in need, lack preparation for the work of caregiver and see their financial security decline, the possibility of abuse happening may well arise out of the gradual caregiver march towards becoming patient himself/herself due to fatigue, anger, depression or resentment.

Discussion

Risk Society Theory and study findings

In an earlier review of this paper, the author was challenged to consider that the patterns identified in the scoping review represented risks to caregiver safety. To consider this challenge, Beck's (1986) Risk Society Theory was reviewed to gain a perspective on the nature of risk and the relevance of risk theory to the identified patterns of caregiver safety.

The Risk Society Theory (Beck 1986) represents a theoretical sociological treatise regarding risk in modernity. Modernity has been variously defined, however, in this paper means,

A society in which the world is open to transformation by human intervention and consists of a complex of economic institutions especially industrial production and a market economy. (Giddens & Pierson 1998, p. 94)

The exponential scientific and technological growth in society to date is recognised and respected by Beck. What bewilders him are the unintended consequences of this growth, which he sees as producing the Risk Society. Beck defines risk as follows:

A future that is prevented, destruction that has not yet happened. (p. 33)

Risk according to Beck is a social construction meaning that humans in action and interaction with each other create risks. Beck's treatise on the Risk Society Theory presents its motive as safety or the prevention of something bad.

In early modernity, the focus of the Industrial Society was the accumulation of wealth, and risk was a part of doing business; yet, capital, labour and government worked in concert to determine wealth and associated risk and how risk would be managed. The nature of the Industrial Society has changed since that of early modernity so that single nations no longer have the authority and accountability to maintain equilibrium in the wealth versus risk equation. Beck (1986) attributes these changes to several processes, which will be explained and discussed in relation to the identified caregiver safety patterns to illustrate why this theory is relevant to the findings and to further understanding of how caregiver safety issues are being constructed in society at large.

Globalisation

The first of these processes is globalisation, which Beck (1986) sees as the back-grounding of the nation-state in favour of global imperatives. These imperatives are set in policy intended to make money for all nations involved. Meeting these imperatives often means relocation of production of goods and services and an erosion of the tax base of individual nations. This erosion of the tax base means the simultaneous erosion of social programmes and the expectation that citizens will assume greater responsibility in all areas of need such as education, health, employment insurance and personal savings (Jarvis 2007).

Home-care demand in Canada increased by 100% between 1995 and 2006. Despite growth in public funding of home care, approximately 4.2% of health budgets are directed to home care (Canadian Healthcare Association 2009, National Association for Home Care & Hospice 2010). In parallel, the Health Council of Canada reported that in 2005, 2%–3% of Canadians received publicly funded home care while 2%–5% was paid privately. This trend means unpaid caregivers can expect to be required to shoulder increasing responsibility in this era of globalisation. Unpaid caregivers who provide 80% of the care for home-care clients are experiencing conscription to the role of caregiver, financial loss, abuse and loss of personal health, placing them outside the zone where harm has not yet happened. Risk's motive is safety, the safety of these caregivers has already been compromised and Risk Society Theory gives us a glimpse into the societal forces at work undermining safety for both the client and caregiver.

Individualisation

The second process at work in Risk Society Theory is individualisation, which means the liberation of the individual, particularly women, from patriarchal domination through access to education, employment and social benefits such as childcare. Personal risk is minimised and individualisation maximised with strong social programmes. This also means that families were freed from the obligation to take care of one another, free to travel and to work anywhere in the world. Individualisation, however, is increasingly at risk with current rates of unemployment, and under-employment which may force many families back together strictly for financial reasons. Through individualisation, the patriarchy was weakened, women had greater access to education, employment and childcare. Ironically, individualisation also means that today's generation does not envision being caregivers,

and places a greater expectation on society to provide for elderly people at a time when the services necessary to support individualisation are being eroded. Today's caregivers are trapped between housing adult children who are unemployed and trying to work and organise care for elderly parents (Pickard 2012). The erosion of social programmes contributes to a claw back of the gains made by women in taking their place in the world of employment, by forcing them to return to care-giving roles and placing their financial situation in peril as illustrated in the pattern identified as financial loss in the data analysis.

Global risks

Lastly, global risks, although not always visible in our day-to-day lives, became so with the recent devastation of the Fukushima Daiichi nuclear plant and surrounding areas in Japan. This was an example of how nuclear technology under certain circumstances produces consequences exceeding anything science can foresee and created risks to society that we can only appreciate at some future point. This disaster will outlast generations and no insurance exists in these situations. Beck (1986) makes the case that in our much lauded scientific and technological growth, we are simultaneously constructing a risk society. The risk society can thrive because the individual nation accountability and responsibility for social programmes have been sacrificed to wealth accumulation for a conglomerate of nations, and technological expansion is occurring at a rate that fails to take into account the full range of consequences (Jarvis 2007).

According to Beck (1986), wealth in society accumulates among the more socioeconomically advantaged, and risk among the socioeconomically disadvantaged. Although all of society is affected by an event such as the Fukushima Daiichi disaster, those who could afford to escape the area will undoubtedly experience fewer long-term effects than those in close proximity who could not afford to move. Similarly, the outstripping of home-care expenditures by those who can purchase private services over those publically funded illustrates that the socioeconomically advantaged can purchase the home care required and will not need to provide it themselves. Those who are less well off and dependent on a cash-strapped public system can expect to assume increasing levels of responsibility in the provision of care to family members in need.

The extent to which the economies of nation-states are intertwined has contributed to a blurring of where the responsibility for attention to risk sits, particularly with technology for which risks are borderless.

How the risk society is being constructed needs to be made visible. The use of Risk Society Theory and the associated processes of globalisation, individualisation and global risks together are intended to illustrate how we as a society are constructing risk. Illuminating how this construction is taking place will enable us to problematise the construction processes and create a possibility in reconstructing the processes in such a way as to work towards affecting change in these processes, thereby positively impacting caregiver experiences in home care.

Conclusion

The four patterns related to caregiver safety identified from the scoping review easily relate to one another. The literature was clear that caregivers found that they were expected to take on the role of care-giving with little or no preparation, making it seem more like conscription than a carefully made decision. Once in the role, they often had to adjust their working lives, leave work, reduce hours, and take lower paying jobs to meet care-giving responsibilities, which in turn led to financial hardship. The longer that care-giving was required and the nature of care provided often determined the rate in decline of caregiver health and may at times have contributed to bidirectional abuse, thereby failing to prevent the risk to caregiver health and safety.

Risk Society Theory and the associated processes provide a macro-level view of the construction of risk in society and health-care in particular. Understanding how these processes construct risk is fundamental to action. Deconstructing the processes that create the risk society requires a fundamental re-commitment to support home-care programmes, and in particular, caregivers nation by nation. The struggle at all levels of society to restore and or preserve these programmes is essential. This fundamental work is necessary to recognise the valuable contribution of caregivers, to preserve hope for existing caregivers and to secure future care for the millions of ageing citizens in our society. A re-commitment to programmes that support the care needs of the ageing will contribute to improved quality of life and safety for caregivers and home-care clients, and to a more sustainable home-care system.

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