

The information worlds of non-resident informal carers: stakeholder perceptions

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EXTENDED ABSTRACT

Purpose of this paper

The aim of this paper is to illuminate the distinctive elements of the information worlds (Burnett & Jaeger, 2011) of informal carers of elderly people, and specifically carers who are not resident with the cared-for person (henceforth non-resident informal carers (NICs)). House of Commons Library (2019) identifies that in 2017/18 there were 4.5 million informal carers in the United Kingdom (UK) alone, with many “sandwich generation” (Grundy & Henretta 2006) carers of both children and parents. Research has shown that, as they age, people increasingly rely on health professionals and family carers for information (e.g. Asla, Williamson & Mills, 2006), with informal carers helping elderly people make sense of the information they receive from healthcare professionals (Pálsdóttir 2012). Surveys of information sources about Covid-19 have shown that older people still use online sources less than younger people to discover health information (Office for National Statistics, 2020).

Studies repeatedly identify informal carers’ frustrations whilst trying to obtain information (e.g. Baxter, Heavey & Birks, 2017). However, there is a paucity of work focusing on informal carers’ information behaviour: Dalmer’s (2020) scoping review noted a lack of work in the information science field. Most studies focus on information *needs* (e.g. Alzougool, Chang & Gray, 2013) or information behaviour relating to specific diseases (e.g. Pálsdóttir 2017). Studies of resident carers predominate, for example, the largest qualitative study (Hepworth, 2004), where the majority were resident, fulltime informal carers (62% spent 100+ hours per week caring).

However, there are particular circumstances when a person is caring at a distance, balancing the responsibilities of their own job and household with that of a remote cared-for person. This study aimed to discover whether stakeholders working closely with both resident and non-resident carers identified differences in the NICs engagement with information, and to map the carers information worlds.

Design/methodology/approach

Indepth semi-structured interviews were undertaken with eleven individuals representing seven stakeholder agencies with missions concerning the support of the elderly or their carers. Participants included workers in charities, independent care agencies, and the social care managers in the City Council, based in one major Northern English city. Stakeholders were interviewed at this stage to get an informed outsider perspective on whether there were distinctive issues associated with non-resident caring, and what these were. Stakeholders were also in a better position to identify macro & intermediate issues. The interviews were audio-recorded and transcribed, and the data analysed inductively, using a combination of Nvivo and manual coding, with the authors initially coding independently, to identify core themes. Policy and advisory documents relating to carers, from national and local government, were also examined. Information Worlds Theory (Burnett & Jaeger, 2011) was used to analyse the micro, meso and macro context.

Findings

Key health-related impacts of being a *non-resident* carer of an older person are as follows: (1) They have less contact with health professionals and formal carers of the cared-for person than do resident carers, and thus less opportunity to seek, receive and share relevant health-related information. This can also make it more problematic negotiating issues of patient confidentiality, in circumstances where obtaining confidential health information would be valuable to both patient and carer. (2) They have limited access to information about the day-to-day care needs and welfare of the cared-for person; for example, whether the cared-for person is eating properly, taking tablets as prescribed, or displaying new behaviours. The cared-for person's own reports may not provide a realistic picture. (3) Their lack of local knowledge means that NICs have less knowledge of local support services and infrastructure. They may miss out on informal local networks that can provide valuable information (e.g. on recommended care homes or medical practitioners) and may be excluded from some support because they are not locally based.

Using the lens of Information Worlds Theory, the impact of national and local policy is evident. Notably, whilst there is a national primary care framework in the UK (i.e. the National Health Service) and national legislation (notably The Care Act 2014), adult social care is devolved to local government (cities or regions), as is implementation of key aspects of the Care Act (including the regulations concerned with information provision) resulting in local variations in policy and practice. The fragmented nature of the care environment, with frequently changing services, aggravates difficulties experienced by carers in maintaining up-to-date knowledge. Thus negotiation of the various information worlds with which the carer has to interact (primary care sector, third sector agencies, commercial agencies, local government) becomes even more challenging for a non-resident.

Research limitations/implications

The main research limitations were that this initial study investigates the perceptions of stakeholders, rather than the carers themselves, and that the participants were based in one city. Resonating with Dalmer's (2019) critique of the official Canadian narrative of "Ageing in Place", situating the UK carers within the broader socio-political context demonstrates the complexity of their challenges, and contrasts with official sanitised narratives of the carer journey or a narrower focus on information sources. The differences in the non-resident carers' experience also highlights the need to identify this characteristic when describing research populations (something which often has been neglected in previous studies).

Practical/social implications

NICs are not identified in policy documents or legislation as having special needs, and have received little research attention. The differences between experiences of resident and non-resident carers have been brought into even sharper relief by lockdowns due to the 2020 COVID-19 pandemic. This study has identified a number of ways in which non-resident carers' needs vary from those of resident carers, and can be used to direct government and third sector agencies to provide more effective support.

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