

## CONFERENCE ABSTRACT

# The integration of formal and informal care provision: An exploratory study of the experiences of primary support persons of chemotherapy outpatients

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Heather Margaret McKenzie<sup>1</sup>, Kate White<sup>1</sup>, Lillian Hayes<sup>1</sup>, Scott Fitzpatrick<sup>3</sup>, Keith Cox<sup>2</sup>, Jo River<sup>1</sup>

1: University of Sydney, Australia;

2: LifeHouse Chris O'Brien Centre, Australia;

3: University of Newcastle, Australia.

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**Introduction:** The integration of health and social care for individual patients depends, in many circumstances, on the involvement (as care providers) of their informal carers or primary support persons. This paper reports on an Australian study exploring the experiences of primary support persons of chemotherapy outpatients. Despite overt reliance on informal/family care provision, and the crucial role of carers in enabling integration of health and social care, little is understood of (i) the impact of this care provision on patient outcomes; (ii) the extent to which primary support persons of chemotherapy outpatients feel the care they provide is well integrated into the overall pattern of service delivery, and (iii) the social, emotional, economic, and physical effects for people providing this care.

**Theory/Methods:** An exploratory, qualitative research design was utilised and a convenience sample of seventeen participants was recruited through the cancer centre at a large tertiary hospital. In face-to-face, semi-structured interviews, participants were asked to identify issues of importance to them as a primary support person of someone receiving chemotherapy, and to provide specific information about their experience of the days following chemotherapy administration. Content analysis led to the emergence of three significant themes.

**Findings:** These themes include: (i) frightened novice to reassuring expert – reflecting the urgency with which primary support persons feel they must develop cancer and chemotherapy related skills and knowledge in order to become an effective care provider; (ii) watching and waiting - encapsulating the range of experiences, from intense vigilance to secretive, monitoring of physical and emotional wellbeing, and (iii) discordance and invisibility – highlighting the extent to which participants felt their support role – although clearly critical to patient wellbeing – is not formally recognised by health professionals and not integrated into the overall pattern of service delivery.

**Discussion:** The overarching conceptualisation of the informal carer role as a 'shadowing' role reflects the ways in which the three themes are connected. This study demonstrates that informal carers in this context do not experience their role as being well integrated into

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established care pathways, or recognised as a significant enabler in the integration of health and social care, including their role in supporting patient self-management strategies, provision of context-specific knowledge, and ensuring that care is person-centred and time efficient. Although this study focuses on one specific clinical area, many aspects of this informal carer experience are likely to be shared by carers of people with other serious health issues. Further research to determine strategies for better recognition of the potential contribution of informal carers to provision of effective integrated care is needed.

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**Keywords:** informal care integration; chemotherapy outpatient support; informal carer role

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