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## Editorial

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# Challenges in Palliative Care Research: Experience from a Randomized Controlled Trial in Refractory Cancer Cachexia

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There is a paucity of research studies in palliative care with less than 1% of clinical trials being relevant to the hospice and palliative care setting.<sup>1</sup> Difficulties in conducting studies with this client group such as recruitment, retention, methodological and ethical issues are well documented within the literature.<sup>1,2-6</sup> Nonetheless, conducting research with palliative populations is necessary to ensure the development of evidence based policies and services which reflect and respond to the needs of this vulnerable and often underserved population. Previous research has demonstrated that palliative care patients<sup>7,8</sup> and their families<sup>9</sup> are willing to be involved in palliative care research and the onus to conduct high quality rigorous research with this client group lies with researchers.<sup>10</sup> It is only through actively engaging in research with the palliative population that we can build an evidence base that will contribute to the development of evidence based policies, protocols and treatments and allow health care professionals to consistently respond to palliative patients and their families in order to maximise their quality of life as they approach the end of their lives.

One of the areas in which this paucity of systematic research has had a detrimental effect on the care of palliative patients is cachexia. The European Palliative Care Research Collaborative's (EPCRC) guidelines<sup>11</sup> on cancer cachexia define it as a multi-factorial syndrome characterised "by an ongoing loss of skeletal muscle mass (with or without loss of fat mass) that cannot be fully reversed by conventional nutritional support" (p. 8). Refractory cachexia<sup>11</sup> refers to the 'stage where reversal of weight loss seems no longer possible' (p. 8) and the majority of patients at this stage will be receiving palliative care. Previous research in this area has demonstrated the holistic impact of the syndrome.<sup>12-15</sup>

Research in palliative care, has been dogged by recruitment problems.<sup>1</sup> Our own research has faced similar problems. In the absence of a recognized treatment solution, an evidence-based psycho-educational health care intervention has been developed for this patient cohort and their family members by a team of researchers and healthcare staff in Northern Ireland. This DVD intervention has been funded by the All Ireland Institute of Hospice and Palliative Care and will be evaluated in a randomized controlled trial with a palliative cancer population who have refractory cachexia.<sup>16</sup> The team's experience thus far highlights the inherent difficulties in conducting research with this client group.

Members of our team have worked closely alongside multidisciplinary clinical colleagues and have engaged in Patient Public Involvement (PPI) from the early stages of the development of the intervention. Their insights were instrumental in: developing the intervention and study information sheets; and ensuring the clinical soundness and practical utility of the psycho-educational intervention. However, our problems with recruitment lie in the fact

that refractory cancer cachexia, while characterized<sup>17</sup> and documented in the EPCRC's guidelines<sup>11</sup> is rarely acknowledged or diagnosed due to a lack of clear clinical diagnostic guidelines and local protocols for clinical management. This reluctance to recognise and diagnose cancer cachexia among the myriad of potential co-morbidities found in end-of-life care has hindered identification of potential participants. Indeed previous research has demonstrated the lack of clinical awareness of this syndrome among health care professionals.<sup>18</sup> While the authors have taken the initiative by: conducting educational sessions on refractory cachexia with health care staff at each clinical site; have harnessed clinical support for the study; and have worked at length with both clinical and PPI colleagues, recruitment into this study has been disappointing.

In order to positively influence clinical practice in palliative care, health care professionals need access to 'best available evidence'. As this and as other studies in palliative care demonstrate, acquiring evidence from this client group presents a great challenge. There is a clear need for the urgent development of evidence based guidelines to aid in the education, diagnosis and management of refractory cancer cachexia. Such guidelines will undoubtedly provide the clinical diagnostic criteria necessary to assist healthcare professionals in identifying refractory cachexia and allow them to respond appropriately. This in turn will make it easier to identify and recruit appropriate patients for future studies in palliative care.

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