OP90 Multiple Myeloma: Developing A Benchmark Patient Experience Index In Australia And New Zealand

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Introduction: Within Australia and New Zealand (ANZ) there is limited evidence regarding the experience and satisfaction across the healthcare system of people living with multiple myeloma (MM). We aimed to quantify the patient experience across the healthcare system to help identify potential areas of the healthcare pathway that could be targeted for improvement to maximize patient satisfaction.
Methods: A 30- to 40-minute online survey was completed by adults in ANZ diagnosed with MM. Anchored best-worst scaling (ABWS) is a technique that takes advantage of an individual's ability to reliably identify extremes ('best' and 'worst') in sets of items, eliciting discriminating rankings free of scale bias. This study implemented a novel anchoring process to rescale importance and satisfaction best-worst scores for factors across the MM healthcare pathway, which could be compared and combined to form a patient experience index (PEI). There were 15 factors or 'moments that matter' (MTM), each describing a different aspect of the patient journey, such as time to diagnosis, treatment logistics, and side effects. The MTM were derived from qualitative research with patients as well as a workshop with key opinion leaders. Additional survey questions were included to help identify potential ways to improve patient satisfaction.
Results: The results were based on 62 patients with MM. The overall median PEI score was 63.1. The top three MTM that were most important to patients, but they were least satisfied with (calculated by combining the top four of each most important/least satisfied factor for each participant), were side effects of medication, effectiveness of medication, and medication access.
Conclusions: The findings from this research contribute to the understanding of patient experiences of treatment and care for MM. The results can inform healthcare decisions for prioritizing interventions that align with patient experiences. In the future, the study could be executed longitudinally to assess shifts in satisfaction within the MM healthcare journey, which would be especially worthwhile if new programs are implemented to improve patient satisfaction.

OP92 The Hidden Burden Of Patients And Families In Rare Diseases: A Scoping Review Of Economic Evaluations

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Introduction: There are more than 7,000 rare diseases (RDs), which are individually rare but have a large collective impact on patients and families, the health system, and society. There are few treatments for RD; where treatments do exist, they are often exceptionally expensive. Understanding the socioeconomic burden (SEB) of RD is crucial to properly valuing these treatments and informing health technology assessment. Our team has developed a framework of cost elements for inclusion in studies of the costs of RDs using an evidence-informed consensus-based approach.
Methods: We conducted a scoping review to identify published economic evaluations studies in RD, searching five electronic databases to identify English language RD studies published 2010-2021. We applied our framework of cost elements to assess studies regarding what cost elements were included.
Results: Of 4,890 records identified, 48 studies were screened for inclusion. Most were from the US (n=27), UK (n=6), and Canada (n=6), and focused on hemophilia (n=14) or cystic fibrosis (n=11). Healthcare system and payer perspectives were most often reported (n=41), with only seven studies reporting a societal perspective. Cost elements most often included were medications (n=41), hospitalizations (n=35), surgery (n=20) medical tests (n=16), and outpatient (unspecified) visits (n=16). Costs to patients, families, and society were less commonly included: productivity (n=5), travel/accommodation (n=3), government benefits (n=2), family impacts (n=0), or other costs relevant to RD (n=1). While unsurprising, given that most analyses focused on healthcare or payer perspectives, this finding illustrates the extent to which the burden of RD is largely unstudied.
Conclusions: Our scoping review demonstrated that most studies are conducted from a healthcare system/payer perspective, and largely consider only medical costs. These studies undercount the hidden burden of rare disease borne by patients and families leading to a gap in our global understanding of the full impact of rare diseases on families. To properly account for the these and value emerging treatments for RD, patient- and family-borne costs must be considered in economic evaluations for health technology assessment.

OP93 The Cost Effectiveness Of Antiretroviral Therapy Adherence Interventions In HIV/AIDS Patients: A Systematic Review Of Decision Analytic Models

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Introduction: People living with HIV/AIDS (PLWHA) frequently struggle to maintain optimal adherence to antiretrovirals (ARVs). Different adherence-improving interventions have been developed and examined through decision analytic model-based health technology assessments. Therefore, we aimed to conduct a systematic review of all decision analytic models developed to improve adherence in PLWHA.

https://doi.org/10.1017/S0266462323001071 Published online by Cambridge University Press