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Determinants of Quality of Care for Adolescents and Young Adults With Chronic Illnesses: A Mixed Methods Study

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Background Measuring the quality of service and user experience is an acknowledged priority for healthcare services; however it seems that healthcare systems have to work very hard to achieve this goal as evidenced by reports of gaps and disparities in the quality of care provided to clients, especially within pediatric and adolescent populations.

Objectives: To identify quality determinants for healthcare services for adolescents and young adults with chronic conditions based on the perceptions and the experiences of adolescents and young adults themselves.

Methodology: A sequential exploratory mixed method design guided this study. The initial qualitative phase employed semi-structured in-depth interviews to elicit the elements and determinants of quality of care as identified by adolescents and young adults living with chronic conditions. The second phase employed a questionnaire developed from the data gathered during the qualitative phase to survey the target population. This was distributed to a larger sample of adolescents and young adults with chronic conditions to determine and confirm the relevance of the identified care elements and quality determinants.

Results: The study revealed 4 main determinants: the provision of adolescent friendly information relating to all aspects of living with chronic conditions, services that facilitate and encourage independence, services characterized by structure with the capacity to be both dynamic and responsive, and finally health care professionals knowledgeable and skilled in relation to adolescent specific issues.

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Background

Measuring the quality of service and user experience is a priority for all industries worldwide. Healthcare services deliver care designed to promote the health and well-being of individuals, many of whom are weak and vulnerable and some who are critically ill and in need of effective and

immediate assistance in order to survive. Ensuring quality healthcare services has been mandated globally for many years (Macias, 2013; Office of Disease Prevention and Health Promotion, 2015; Smith, Saunders, Stuckhardt, & McGinnis, 2013). It seems that healthcare systems struggle to achieve this goal. An extensive literature describes gaps and disparities in the quality of care provided to clients, including the care offered to vulnerable pediatric and adolescent populations (Annunziato et al., 2013; Bamford et al., 2001; Beacham & Deatrck, 2015; Berdahl et al., 2010; Betz,

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2013; Institute of Medicine, 2007; Lannon & Peterson, 2013; Macias, 2013; Mangione-Smith et al., 2007; Mitka, 2008; Park, Scott, Adams, Brindis, & Irwin, 2014; Perrin & Homer, 2007).

A definitive definition of 'quality' as it relates to healthcare service remains elusive. Mosadeghrad's (2013) identified stakeholders' perceptions and expectations of quality as 'excellence, value, conformance to standards and meeting customer needs and expectations' (p. 215). However, different emphasis is placed on discrete aspects of this 'definition' by policy makers, managers, service providers and clients. Identifying specific indicators or determinants of quality healthcare and measuring these regularly is thus of great importance, if healthcare institutions are to monitor the quality of current service delivery, to assess the effectiveness of quality improvement initiatives, and to benchmark against other institutions (Mainz, 2003; Sawyer, Ambresin, Bennett, & Patton, 2014).

While progress has been made in ensuring quality for some areas of healthcare delivery for adults, the same degree of attention has not been given to the care of adolescents and young adults. However, this group of healthcare service users have a different experience of illness and health care compared with adults (Al-yateem & Docherty, 2015; Frech, 2014; Hargreaves, Sizmur, & Viner, 2012; Office of the High Commissioner for Human Rights, 2015; Patton et al., 2012; Sawyer et al., 2014; Tylee, Haller, Graham, Churchill, & Sanci, 2007). The need to define quality indicators for adolescents and young adults arises from physical, psychological and developmental needs specific to this period of development and the nature of health problems and illness experiences. Adolescent and young adults' views on the quality of service they both require and receive are markedly different from those expressed by children and adults. Despite being recognized as important, it is widely acknowledged that as a group adolescents and young adults' participation in service planning has been overlooked (Ambresin, Bennett, Patton, Sanci, & Sawyer, 2013; Frech, 2014; Hargreaves et al., 2012; McIntyre, 2007; Patton et al., 2012; Royal College of Paediatrics and Child Health, 2015; Tylee et al., 2007).

The voice of the 'patient' describing the 'patient experience' has increasingly become an important indicator and motivator for the evaluation and further development of healthcare systems (Australian Commission on Safety and Quality in Healthcare, 2012; Betz, Lobo, Nehring, & Bui, 2013; Patient-Centered Outcomes Research Institute (PCORI), 2015; Sawyer et al., 2014; Sharma, O'Hare, Antonelli, & Sawicki, 2014). It is argued that service components and quality of care determinants are more relevant, efficient and have more of an impact on the care provided when they are derived from the experiences and perceptions of the service users themselves. This paper reports on a study that sought to identify the service components or quality determinants that adolescents and young adults with chronic illness deem essential.

Cystic fibrosis (CF) is considered to be the most common chronic and life-limiting condition that affects children in the developed world. Thus, adolescent and young adult patients with CF were chosen to represent the needs of other adolescents with chronic health conditions. CF is a genetically acquired, progressive chronic disease that mainly affects the respiratory and gastrointestinal systems within the body. It causes breathing difficulties, frequent chest infections and delayed growth, and many other potentially serious complications (Goljan, 2007). The treatment regimen for CF is complex, requiring dietary restrictions and replacements, multiple medications, inhalers and chest physiotherapy.

The study was undertaken in the Republic of Ireland which has both a high prevalence of CF and mature hospital and community services. Existing literature indicates that the needs of adolescents and young adults with chronic illness in healthcare institutions tend to be similar globally therefore choosing Ireland for this study is not considered a limitation (Kyngas, 2000; Scal, 2002; Schmidt, Petersen, & Bullinger, 2003; Shaw, Southwood, & McDonagh, 2004; Wollenhaupt, Rodgers, & Sawin, 2012).

Aim

The aim of the study is to recommend quality determinants for the healthcare service for adolescents and young adults with chronic conditions, based on the perceptions and the experiences of the adolescents and young adults themselves.

Study Methodology

The research utilized a sequential exploratory mixed method design (Creswell, 2013) where the first qualitative phase of the study informed the second quantitative phase of the study. This design is particularly useful where the researcher seeks firstly to understand the desired phenomena prior to conducting a quantitative study. This approach is appropriate to the objectives of this study, where an initial exploration of adolescents' and young adults' perceptions of the quality of service they receive guides the second phase of the study in which larger number of service users were surveyed. Figure 1 presents the study phases.

Phase One

The initial phase was a qualitative component that utilized in-depth interviews with the aim to explore adolescents' and young adults' views about the service components that determine quality and that should be present in any healthcare system.

Sampling for the In-Depth Interviews (Phase 1)

Selection criteria for the study focused on adolescents and young adult patients with CF, who were receiving care and treatment in pediatric or adult settings, aged 15–20 years, representing the mid to late adolescence and young adulthood stages of development. Individuals were excluded

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