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Review Article

Patient-Centered Strategies to Improve Radiographic Practice for Patients with Down Syndrome: A Systematic Review

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ABSTRACT

Background: Down syndrome is a common human genetic disorder caused by trisomy of chromosome 21. Individuals with Down syndrome can present with a range of health issues during their lives that may require imaging for diagnosis. Radiographers, therefore, play a significant role in the management and communication of Down syndrome patients' health.

Purpose: This review identified patient-centered strategies that radiographers should use to provide quality imaging services for Down syndrome patients, who may have limited verbal ability and behavioral issues.

Method: A systematic review using the established PRISMA guidelines was undertaken of current literature obtained through the Ovid and Scopus databases. A total of 189 articles were found, of which 41 were categorized and analyzed in detail.

Findings: A high level of care for Down syndrome patients will require longer than usual procedures, and the patients will not respond well to being rushed or ignored. Down syndrome patients have difficulty verbalizing, yet they understand more than is often thought. Individuals may require increased imaging time to give them time to respond, especially to pain. Patients are at risk of injury with AAI or other pathologies, and caution should be taken with flexion and extension spine x-rays. Radiographs may reveal undisclosed physical abuse.

Conclusion: Specific strategies with verbal and nonverbal communication help to facilitate communication, reduce anxiety and fear, and improve compliance with Down syndrome patients. Patients may require an increased level of care; increased imaging time; and allowing support people to be present during the examination process.

RÉSUMÉ

Contexte : Le syndrome de Down est un trouble génétique commun causé par la trisomie du chromosome 21. Les personnes avec le syndrome de Down peuvent présenter différents problèmes de santé qui nécessitent de faire appel à l'imagerie diagnostique durant leur vie. Les radiographes jouent donc un rôle important dans la gestion et la communication de la santé des patients ayant le syndrome de Down.

But : Les auteurs ont recensé des stratégies axées sur le patient que les radiographes peuvent appliquer pour fournir des services d'imagerie de qualité pour les patients atteints du syndrome de Down, qui peuvent avoir des capacités verbales limitées et des problèmes de comportement. Méthodologie: Un examen systématique de la littérature actuelle tirée des bases de données Ovid et Scopus a été effectué, en appliquant les lignes directrices PRISMA. Au total, 181 articles ont été trouvés, dont 41 ont été catégorisés et analysés en détail.

Constats : Un niveau élevé de soins pour les patients atteints du syndrome de Down exige d'accorder plus de temps pour les procédures et le patient réagit mal au fait d'être brusqué ou ignoré. Les patients atteints du syndrome de Down ont de la difficulté à verbaliser mais comprennent plus souvent qu'on ne le croit. Ces personnes peuvent avoir besoin de plus de temps d'imagerie pour avoir le temps de réagir, notamment à la douleur. Ces patients sont à risque de blessures dues à l'instabilité atlanto-axiale (IAA) et d'autres pathologies, et des précautions doivent être prises lors des radiographes de la colonne vertébrale en extension et en flexion. Les radiographies peuvent également révéler des abus physiques non divulgués.

Conclusion : Des stratégies spécifiques, faisant appel à la communication verbale et non verbale, aident à faciliter la communication, à réduire l'anxiété et les peurs et à améliorer la conformité des patients atteints du syndrome de Down. Les patients peuvent avoir besoin

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d'un niveau de soin plus élevé; d'un temps d'imagerie plus long; et de la présence e personnes de soutien durant le processus d'examen.

Keywords: radiography; systematic review; Down syndrome; patient-centered care

Introduction

Down syndrome (also known as Trisomy 21) caused by trisomy of chromosome 21 is one of the most common and recognizable genetic abnormalities in humans [1–4]. One in every 700 to 900 babies are estimated to be born with Down syndrome globally, and in 2013, around 13,000 babies were diagnosed with Down syndrome in Australia [5]. Individuals with Down syndrome share a combination of distinct physical characteristics (flat nasal bridge and facial profile) and cognitive difficulties (intellectual disability and behavioral problems) [3]. Individuals with Down syndrome are also more likely to develop health problems including, but not limited to: congenital heart defects (40%–60% occurrence), obstructive sleep apnea (50%–75% occurrence), and orthopedic complications (20% occurrence) [2, 3]. More than 80% of the population with Down syndrome lives into adulthood, with an average life span of 60 years [6].

This review identified patient-centered strategies radiographers can use to provide quality medical imaging services for patients with Down syndrome. Patients with Down syndrome are likely to undergo a variety of medical imaging procedures throughout their lives for the diagnosis of health problems, including plain x-ray procedures, computed tomography (CT), and magnetic resonance imaging (MRI). Radiographers are key in the management and provision of quality health care services for patients with Down syndrome. However, patients with Down syndrome can present challenges for radiographers who may be unaccustomed to their clinical and behavioral presentations. As such, patients with Down syndrome require an increased level of care, and this review aimed to examine strategies radiographers can adopt (including nonverbal communication, increasing imaging time, and involving support people) to better manage and deliver medical imaging to individuals with Down syndrome.

Methodology

A systematic review of current literature was undertaken. The process allows conclusions to be drawn from examination of the literature by relevance, quality, and methodology [7]. There are a number of recognized approaches to conducting systematic reviews [8–10]. In this case, the PRISMA guidelines for conducting systematic reviews [11] have been adopted. The research question was: What patient-centered strategies can radiographers use to provide quality medical imaging services for patients with Down syndrome?

The Ovid and Scopus databases were searched using keywords: *Down syndrome*, *communica**, *radiograph**, *manag**, *interact**, *challenge*, and *imag**. One author reviewed the titles and abstracts of the retrieved articles. Current research

examining radiographers' interactions with patients with Down syndrome received only two results, neither of which considered optimal delivery of imaging services for these patients. The search was then revised to include health care, nursing, occupational therapy, and physiotherapy to consider transferrable skills and strategies for radiographers to use to communicate, interact with, and care for patients with Down syndrome. Articles were included if they examined patients with Down syndrome in an primary care and/or allied health setting (including health care, nursing occupational therapy, and physiotherapy) and mentioned interventions or strategies used to facilitate management of these patients. Articles were excluded if they were not published in English language, and Down syndrome was not discussed in relation to health care management. No time limits were imposed on the search. This resulted in articles that discussed common medical complications of Down syndrome and patient-centered care (see Figure 1).

Data were extracted by one author to ensure consistency, using the PRISMA checklist. The data extracted from the studies included details about the participants (sample size and demographic characteristics), setting, study methods, and findings. All studies that met the inclusion criteria were then assessed for quality using the critical appraisal skills programme checklist.

Findings

A total of 189 articles were identified from the revised search criteria, and exclusions were then applied. A total of 69 articles were identified as relevant. These articles were read in detail. A further 28 articles were excluded because they were primarily related to issues not transferrable to the radiography context. This resulted in 41 articles forming the basis of this review. A flow chart has been included to illustrate the search process.

The review revealed two key outcomes for radiographers when imaging patients with Down syndrome. The first relates to the common medical conditions associated with Down syndrome and the potential impact on diagnostic imaging procedures. The second outcome relates to patient-centered care and the management of patients with Down syndrome. It is beyond the scope of this article to present details of diagnosis of pathology for patients with Down syndrome. The pathology is discussed only insofar as it relates to patient management.

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