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題目 (Title):

福萊德瑞克氏運動失調症兒童及其家庭對於物理治療服務所感知的成效及阻礙

(Perceived Effectiveness and Barriers to Physical Therapy Services for Families and

Children With Friedreich Ataxia)

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目的 (Purpose):

描述物理治療介入於福萊德瑞克氏運動失調症兒童的頻率、型式和可感知到的成效，定義影響治療的阻礙因素和徵求父母的意見。

(To describe the frequency, type, and perceived effectiveness of physical therapy interventions for children with Friedreich ataxia (FA); identify barriers to therapy; and solicit advice from parents.)

方法 (Methods):

30 位具有福萊德瑞克氏運動失調症兒童的父母參與此半結構化面談，並將蒐集所得數據以量化和質化方法進行分析。

(Parents of 30 children with FA participated in semistructured interviews. Qualitative and quantitative methods were used to analyze the data.)

結果 (Results):

參與研究的 67% 兒童接受直接物理治療服務，以進行伸展和肌力訓練運動為主，

且年齡越大的兒童其感知運動的有效性越高。73%的兒童接受居家運動方案，9%兒童則同時執行這些方案。外在阻礙包括：缺乏有經驗的服務提供者和有限的給付。內在的阻礙則為有限的時間和精力、缺乏對服務的覺知和缺乏針對兒童不同的喜好來設計方案。父母建議治療師應扮演專家、倡導者和採取以家庭和兒童意願為基礎的服務方法。

(Sixty-seven percent of children received direct physical therapy service. Stretching and strengthening exercises were used most frequently, and their perceived usefulness increased as the children aged. Seventy-three percent received home exercise programs; 9% implemented these consistently. External barriers included a lack of expert providers and limited reimbursement. Internal barriers included limited time and energy, lack of awareness of services, and children's preferences not to be treated differently. Parents advised therapists to become experts, advocates, and use approaches based on family and child preferences.)

結論 (Conclusions):

結果可提供未來發展福萊德瑞克氏運動失調症兒童之研究、教育和有效介入的起點。

(Outcomes provide a starting point for developing further research, education, and effective interventions for children with FA.)

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