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The Recommendation of Disability Allowance for Paediatric Haematology and Oncology Patients

ACW ***LEE***

Abstract Patients with disabling illnesses may be eligible for the Disability Allowance under the Social Security Allowance Scheme of the Social Welfare Department. The definition of severe disablement under the Scheme, however, is not directly applicable for the paediatric patient. A questionnaire survey was conducted to examine the recommendation made by paediatricians working in public hospitals on 19 pre-selected haematological and oncological disorders. The respondents consisted of paediatricians not specialised in haematology and oncology ("non-specialists") and paediatricians working in the field ("specialists"). Twenty-three (53%) of the 43 questionnaires distributed were returned. A consistent response in the recommendation of Disability Allowance was seen in 13 out of 19 conditions, in which over 80% of the respondents had the same reply. Discrepant responses were seen in the remaining conditions. Respondents also differed in their waiting period when discontinuing the recommendation after completion of anticancer chemotherapy. Discrepancies occurred not only between "specialists" and "non-specialists", but also among "specialists". Potential conflicts may arise when patients with the same medical condition are treated differently by different doctors, or from hospital to hospital.

Key words Decision making; Haematologic diseases; Oncology service; Social security

Introduction

Under the Social Security Allowance Scheme, any person who is severely disabled is eligible for Normal Disability Allowance (DA).[1] In addition, if the disabled person requires constant attendance in relation to his bodily functions from others, he/she may be eligible for the Higher DA.[1] The eligibility criteria for Normal DA and Higher DA have been set by the Social Welfare Department and are summarised in Table 1 and 2, respectively. The current monthly benefits for Normal DA and Higher DA are HK$1,260 and HK$2,520, respectively.[2]

It has been the author's experience (unpublished observation) that children with chronic and significant medical illnesses often approach their paediatricians in public institutions for certification and application of DA. Except for the occasional patient who has the obvious features as listed in items (i) to (vii) of Table 1, the majority of cases have "other conditions resulting in total disablement". Since there are no listed conditions that do or do not qualify for total disablement that is "broadly equivalent to a person with a 100% loss of earning capacity",[3] the certifying paediatrician has to rely on his personal and professional judgement when making the recommendation.

Therefore, a questionnaire survey was conducted to examine the variability of response from two groups of paediatricians over a range of haematological and oncological disorders.

Materials and Methods

The questionnaire was sent to two groups of respondents: (1) paediatricians who were not specialised in haematology and oncology working in the paediatric department of Tuen Mun Hospital (the "non-specialists"), and (2) paediatricians specialised in paediatric haematology and oncology working in Prince of Wales Hospital, Princess Margaret Hospital, Queen Elizabeth Hospital and Queen Mary Hospital (the "specialist"). Each respondent was required to check on a list of medical

Department of Paediatrics, Tuen Mun Hospital, Tuen Mun, New Territories, Hong Kong, China

ACW **LEE** （李志偉） *MRCP, FHKAM(Paediatrics)*

Correspondence to: Dr ACW **LEE**

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Table 1 Physical conditions that meet the requirement for Normal Disability Allowance[1,3]

This means that a person is in a position broadly equivalent to a person with a 100% loss of earning capacity according to the criteria in the First Schedule of the Employees' Compensation Ordinance (Cap. 282):

(i) Loss of functions of two limbs
(ii) Loss of functions of both hands or all fingers and both thumbs
(iii) Loss of functions of both feet
(iv) Total loss of sight
(v) Total paralysis (quadriplegia)
(vi) Paraplegia
(vii) Illness, injury or deformity resulting in being bedridden
(viii) Any other conditions resulting in total disablement

To qualify for an allowance, the person must also be certified by the Director of Health or the Chief Executive of Hospital Authority (or under exceptional circumstances by a registered medical practitioner of a private hospital) that his disabling condition within the meaning of the scheme will persist for at least 6 months.

Table 2 Additional criteria to qualify for the Higher Disability Allowance[1,4]

In addition to being totally disabled broadly equivalent to a person with a 100% loss of earning capacity, the person also requires from another person:

(a) frequent attention throughout the day and prolonged or repeated attention during the night in connection with his bodily function, or
(b) continual supervision in order to avoid endangering himself or others.

For a patient under 15, he or she must also require constant attention and supervision substantially in excess of that normally required by a child of the same age and sex.

conditions and indicate if DA was recommended, and whether Normal DA or Higher DA was recommended. They were also asked when they would stop recommending DA if a cancer patient or a bone marrow transplantation (BMT) recipient had completed treatment successfully.

The responses from non-specialists and the specialists were first counted as a whole for the consistency of recommendation of DA. The response was regarded as consistent if more than 80% of the respondents would or would not recommend DA for a certain medical condition. For conditions with non-consistent responses, the responses from non-specialists and specialists were compared using the two-tailed Fisher's Exact Test of the SPSS for Windows 7.5.

Results

Twenty-eight questionnaires were distributed to the non-specialists and 14 (50%) were returned. Fifteen questionnaires were sent to the specialists and 9 (60%) were collected. Their overall responses are listed in Table 3. Of the 19 conditions listed, consistent recommendation was evident in 13 disorders. Thus, paediatricians would generally recommend DA for children with thalassaemia major, severe aplastic anaemia, all kinds of leukaemias, solid tumours with permanent physical or mental complications, and BMT recipients with extensive chronic graft-versus-host disease. Patients with thalassaemia intermedia or hereditary spherocytosis not requiring blood transfusion, acute idiopathic thrombocytopenic purpura (ITP), and mild aplastic anaemia would not be qualified to receive DA.

For the remaining conditions, the comparison of responses between the specialists and non-specialists were tabulated in Table 4. Discrepancy between the specialists' and the non-specialists' responses were more evident for patients with thalassaemia intermedia requiring blood transfusion, solid tumour without permanent complication, and BMT recipients without major complications. When compared, the specialists were more likely to recommend DA for these conditions. However, the variable responses were equally encountered among non-specialists and specialists in the other three diseases, namely, thalassaemia major not on chelation, hereditary spherocytosis not requiring blood transfusion, and chronic severe idiopathic thrombocytopenic purpura.

As to the question when the paediatrician would stop recommending DA after completion of treatment, there was a consistent response for BMT recipients. Seventeen out of 19 (90%) respondents would wait for a certain period, and they would stop the recommendation at a median of 12 months (range two to 24 months). For cancer

Table 3 The overall responses on the recommendation of Disability Allowance

Conditions	Number of responses (percentage)		
	No DA	Normal DA	Higher DA
Thalassaemic syndromes			
Thalassaemia major w/o chelation	13 (56.5%)	10 (43.5%)	0
Thalassaemia major with chelation	4 (17.4%)	18 (78.3%)	1 (4.3%)
Thalassaemia intermedia requiring blood transfusion	12 (52.2%)	11 (47.8%)	0
Thalassaemia intermedia not requiring blood transfusion	23 (100%)	0	0
Other haematological disorders			
Spherocytosis requiring blood transfusion	15 (65.2%)	8 (34.8%)	0
Spherocytosis not requiring blood transfusion	23 (100%)	0	0
Acute ITP (platelet <20 x 10^9/L)	23 (100%)	0	0
Chronic ITP (platelet <20 x 10^9/L)	13 (56.5%)	10 (44.5%)	0
Aplastic anaemia, mild	19 (86.4%)	3 (13.6%)	0
Aplastic anaemia, severe	4 (17.4%)	16 (69.6%)	3 (13%)
Malignancies			
ALL, normal-risk	3 (13.6%)	14 (63.6%)	5 (22.7%)
ALL, poor-risk	3 (13.6%)	14 (63.6%)	5 (22.7%)
Acute myeloid leukaemia	3 (13.6%)	13 (59.1%)	6 (27.3%)
Chronic myeloid leukaemia/JCML	3 (14.3%)	14 (66.7%)	4 (19.0%)
Tumour, no permanent complication	8 (34.8%)	13 (56.5%)	2 (8.7%)
Tumour, permanent motor complication	1 (4.5%)	15 (68.2%)	6 (27.3%)
Tumour, permanent mental complication	1 (4.5%)	14 (63.6%)	7 (31.8%)
Bone marrow transplantation recipients			
No major complication	11 (52.4%)	7 (33.3%)	3 (14.3%)
Extensive chronic GVHD	2 (9.5%)	7 (33.3%)	12 (57.1%)

Not every respondent had completed all the items and the total number of responses per item may be less than 23.

Abbreviations: ALL, acute lymphoblastic leukaemia; DA, Disability Allowance; GVHD, graft-versus-host disease; ITP, idiopathic thrombocytopenic purpura; JCML, juvenile chronic myeloid leukaemia; w/o, without.

Table 4 The difference in responses between specialists and non-specialists

Conditions	Recommendation for DA		p values
	No	Yes	
Thalassaemia major without chelation			
Non-specialists	10	4	0.102
Specialists	3	6	
Thalassaemia intermedia requiring blood transfusion			
Non-specialists	10	4	0.036
Specialists	2	7	
Spherocytosis requiring blood transfusion			
Non-specialists	10	4	0.657
Specialists	5	4	
Chronic idiopathic thrombocytopenia purpura			
Non-specialists	9	5	0.417
Specialists	4	5	
Tumour without permanent complication			
Non-specialists	8	6	0.007
Specialists	0	9	
BMT recipient without major complications			
Non-specialists	9	3	0.03
Specialists	2	7	

cases, however, six (28.6%) respondents would stop recommending DA immediately after completion of treatment whereas 15 (71.4%) would wait for a median interval of six months (range one to12 months). Specialists were more inclined to wait when compared with non-specialists (9/9 vs. 6/12, p=0.019).

Because of the small sample size, the difference in the response on whether Normal DA or Higher DA is recommended cannot be meaningfully analysed.

Discussion

Disability Allowance (DA) is part of the Social Security Allowance Scheme under the operation of Social Welfare Department.[1] The scheme is designed to provide non-contributory allowance to the severely disabled and elderly Hong Kong residents to meet the special needs arising from disability or old age. According to the eligibility criteria set out by the Social Welfare Department, severe disability may fall into one of the three conditions: (1) disabling physical condition or blindness, (2) disabling mental condition, and (3) profound deafness. To qualify for an allowance, the person's disabling condition must be certified to be lasting for at least six months. For the year 1998/99, a total of HK$1,321 million have been paid to 81,741 cases as DA.[2]

Patients with chronic physical illnesses may be eligible to DA under the category of "any other conditions resulting in total disablement".[1] According to the instructions of the Social Welfare Department, "total disablement" means that a person is in a position broadly equivalent to a person with a 100% loss of earning capacity even though he or she may have taken up employment. In the newly revised Medical Assessment Form under the Social Security Allowance Scheme,[3] additional conditions are listed to define severe disablement when the patient's physical or mental illness does not fall into an easily definable handicap (Table 5). While the implication of these conditions and criteria for the adult patient is clear, its applicability to the paediatric patient needs further interpretation. As there are no explicit instructions on what constitute total disablement in children, the recommendation for DA has to be relied on the personal and professional judgement of the prescribing paediatrician.

This is the first study in Hong Kong in which the medical recommendation of DA in children is looked at. As it is not practical to focus on all paediatric diseases, a list of haematologic and oncologic disorders has been chosen to examine the variability of recommendation among paediatricians with respect to DA. The results of the study show that paediatricians working in public hospitals have a high degree of consistency towards DA recommendation in the majority of selected medical conditions. A larger sample of paediatricians from more hospitals is needed before the observation can be generalized.

However, there is still significant disagreement among the respondents on certain disease entities. For patients with solid tumours without permanent complication and BMT recipients without major complications, there is a significant difference in the responses between specialists and non-specialists. The sophisticated nature of childhood cancers and BMT may be the underlying factor to account for the discrepancy. For other conditions such as thalassaemia major not on iron chelation therapy, hereditary spherocytosis requiring blood transfusion treatment, and chronic severe thrombocytopenic purpura, the difference in responses cannot be accounted for by the specialist status. Similar problem is also observed with respect to the timing of discontinuation of DA after completion of cancer therapy. The limited number of respondents may have underestimated the size of discrepancy in other clinical entities. Such discrepancy may create potential embarrassment and conflict when patients with similar medical condition do not receive the same recommendation to DA within the same hospital or among different hospitals.

Because of the small and simplified scale, the results of this study should not be taken as the standard for use in clinical practice. However, more specific guidance is needed when children are assessed on their medical grounds for eligibility of DA. This would help to prevent potential conflicts arising from the variability of interpretation of disablement, and to improve the

Table 5 Conditions broadly equivalent to 100% loss of earning capacity

A significant restriction or lack of ability or volition to peform the following activities in daily living to the extent that substantial help from others is required in any one of the following areas:

(1) working in the original occupation and performing any other kind of work for which he/she is suited;

(2) coping with self-care and personal hygiene including feeding, dressing, grooming, toileting and bathing;

(3) maintaining one's posture and dynamic balance while standing or sitting, for daily activities, managing indoor transfer (bed/chair, floor/chair, toilet transfer), travelling to clinic, school, place and work; and

(4) expressing oneself, communicating and interacting with others including speaking, utilizing social (community) resources, seeking help from others, and participating in recreational and social activities.

accountability of utilization of social security. A consensus recommendation on various medical conditions made by specialists is a possible way of providing uniform treatment to patients with similar illnesses.

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